TRACING PATHS:

THE SOCIAL HISTORICAL ORGANIZATION OF MENTAL ILLNESS IN ONTARIO

by

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Abstract

This thesis employs a critical ethnographic and social historical lens to make visible the experiences of people from within Ontario's mental health system. Social historical analysis of texts that governed Ontario's psychiatric hospital system from the end of the nineteenth century to the present mental health system provide context to 30 ethnographic interviews with 15 people who identified as consumers/survivors and 15 people who identified as stakeholders or service provider/caregivers in northern Ontario. Contextualized from below and within and from the past to the present, this interrogation of the mental health and psychiatric system adds to the body of literature on mental illness by adding voices of knowledge and experiences of mental illness. It raises important questions about the shifting landscape of the mad subject. The thesis focuses in particular on the ways in which present mental health consumers, survivors, service/providers, caregivers and stakeholders navigate through the system. It concludes with a discussion of the absence and necessity of first person accounts of madness and the mental health system.

Keywords

Mental Health, Mental Illness, Madness, Mad Knowledge, Consumers, Survivors, Psychiatry, Ontario, Critical Ethnography, Social History, Anti-psychiatry, Governmentality

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This thesis is about the experiences of Christopher, Cassie, Brent, Pete, Holly, Leo, Quinn, Marcy, Jane, Steven, Simon, Brian, Sam, Patrick and Laura, all of whom have experienced the mental health system in quite different ways. We also have the honour of hearing from Maggie, Mischa, Sean, Dave, Sally, Layla, Jack, Collin, Kelly, Julie, Paddy, Sophie, Rhonda, Tim and Dannie. Of this group, many are people I see from time to time and they ask about the thesis. Others are or have become friends and yet others are people I rarely see. I thank everyone of this group for sharing your time, experience, wisdom, humour, imagery, expertise, painful memories, frustrations, memories and reflections with myself and the readers of this thesis.

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I liked Gratien Allaire as soon as I met him. He asked me difficult questions and pointed with authority to frivolous and inconsequential things I was paying too much attention to. He hoped, I think, to spare me the burden of getting lost in the dark forest of social history. I got lost anyway—quite lost, and Gratien pulled me out. An interdisciplinary thesis would simply not be possible without such expertise and the willingness to share this knowledge and time.

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Chapter One: Introduction

1.1 Introduction: Locating Madness

The social history, organization and contemporary experiences of mental illness and the mental health system are the focus points and interrogative positions of this thesis. Critical analyses of the mental health system as it is experienced by selected people from Ontario, Canada are brought to bear on the history of the mental health system from its asylum beginnings in Ontario to the community care model. The particular ways that people engage with and experience the present mental health system opens up for critical analysis both the present and subjective experiences from within the system and the past as well as the appearance of madness as a social problem. The solutions to madness have changed; that it *is* a problem has not. The thesis appreciates and takes seriously mad knowledge as it is written by critical scholars and psychiatric survivors as well as experiences from inside modern day asylums, mental health waiting rooms, counsellors' offices, prisons, kitchens and coffee shops. This knowledge and these ways of knowing interrupt psychiatric history and contemporary versions of mental illness and mental health.

Through close and analytical reading of the experiences of people accessing and delivering services in the mental health system a *genealogical* analysis works to critically analyze the appearance of the mad subject in history. As well the narrowing of limit experiences of humanness as a consequence of mental health talk is considered. Finally, the precarity of

madness as a casualty of increasingly efficient models of bioengineering is considered. "Genealogy", writes Úna Crowley, "works on the limits of what people think is possible, not only exposing those limits and confines but also revealing the spaces of freedom people can yet experience and the changes that can still be made" (Foucault, qtd. in Crowley 2). A genealogy of madness exposes what is at risk beyond the mad person him or herself as certain humans are erased from the possibility of being through an analysis of what threats they might pose to themselves and others. We are witnessing the emergence of a madness that gets under the skin and into the mind. With or without a diagnosis its potential, its risk of coming to fruition is watched, monitored and tracked. Despite the conceptual ambiguity of madness or mental illness, outside of objective and codified agreements on sets of behaviours and corresponding corrective or ameliorating protocols, it continues to occupy a central place as a social problem in Canada. Moral treatment was brought to bear on the problem. Institutions were built to contain it. From these institutions, those most concerned with the problem had a better view of it, even when it was very dark—they could still *hear* the problem and sought about describing it. When it was agreed that it was cruel to chain the mad to walls, the chains were loosened only to retain a grip of a different substance. Psychotropic drugs were brought to bear on the problem. The people with the problem were released, with their medication, to the streets and new models of regulating and watching them were implemented. Over time, it became clear that the search for a solution to the problem of madness, although it had not been defined, was not going far enough. The experts came at the problem from the opposite end of the spectrum—where madness could not be allowed to exist— and the mental health movement was born.

In recent years, talk about Canadian mental health has reached saturation as a mental health movement campaigns strenuously for more awareness. Mental illness and mental health

are discussed publicly under a newer rubric that excludes all but those who survived and triumphed over mental illness. The past century has also seen a dramatic change in the institutional organization of what is currently called mental illness. For instance, the former "patient" is, unless incarcerated, referred to as a "consumer" or "client" in recognition of her/his capacity for autonomous decision-making. This prescribed capacity coincides with the restructuring of relatively new mental health service models. I argue that current mental health consumers and survivors, inscribed with autonomous decision making responsibilities and privileges represent a new wave of seeing madness within oneself. This perspective is held in tension with increasingly micro regulated social spaces in which all but carefully managed social behaviour is negatively sanctioned. The message is that it is okay to have mental health crises and it may even be okay to be a bit productively mad, but not in this way and certainly not in these spaces. Madness is as carefully managed and regulated as ever. Caregivers and service providers are caught up in this bind as well as regulative language and funded, prescriptive modalities overtake more holistic and traditional ways of engaging with extremes of existential crisis, anxiety and depression.

This thesis is about experiences of the current mental health system in Ontario. It hears from within this system and analyzes the experiences of those who have accessed services and those who have provided services or care within this system. As well, it hears from those who oppose and resist the current mental health system and offers a place of critical analysis outside and against this system. The work makes visible the ways in which psychiatric power has evolved from having physical spaces set apart for the confinement and treatment of the mad to current, more subtle practices of constraint. The people who shared their experiences described a dividing line that separates two worlds. The distinction is not between those who are mad and

those who are not — a distinction to be made during the asylum era; instead the distinction is between those who can diagnose and treat madness and those who have had mad experiences.

The consumers and survivors interviewed for this thesis described entering a mental health system through which they learn to live carefully, to suspend or repress some aspects of their being in order to gain relief from other aspects, to make their own meanings out of madness and to renegotiate the terms of their existence under the canopy of a mental health diagnosis.

Some of the service providers described increasing constraints in their work and spoke of the necessity and the limits of the language of diagnosis. The discussion centres on the limitations as well as the constraints of language to account for and to care for madness and mad people respectively. As well, analyses of how both madness and diagnoses of madness impact and constrain behavior are discussed. Relationships to oneself, to others and to the mental health service industry show up in various exchanges and economies. This new form of power, disguised sometimes as autonomy and responsibility is internalized in unique ways in the contemporary mad person. The thesis concludes with discussion built from analyses of Ontario's psychiatric history, the present mental health system, and the ways in which this is socially organized in the present.

The story of madness in human history includes the romantic notion of loving madly, of losing all sense of reason in the pursuit of answers to philosophical, mathematical, or religious questions, and of experiences of despair and terror that stretch the full range of human experience to its most uncomfortable limits. The story of madness is also one of medicalizing, classifying and rehabilitating the discomfort and danger of being human. In Canada, this is a story and a history of experimentation and incarceration—the psychiatrization—of mad people. Although much has been written, especially relatively recently, about people considered to be

insane and the institutions that confined them, less has been written about the evolution of the mental health consumer and the mental health survivor and the history that has made such an entity possible. Madness, once a subject of secrecy and alienation, is now a thriving research subject linked to an equally thriving industry of research and literature on mental health and wellness. From self-help books and self-help programs to institutional mandates to provide more support for the so-called mental health crisis, it seems that everybody is talking about madness, by any other name.

The thesis understands the history of psychiatry as encompassing at least two transitions. The first of these, discussed in Chapter Three, corresponds to Ontario's institutional history and in this era the distinctions between patient and doctor, prisoner and warden, madness and sanity, deviance and normal behavior were quite clearly drawn. Geoffrey Reaume writes of the terminology used to mark the distinctions between inmates and officials and says that the terminology "carries with it potent visual images that have come down through history to make people with mental disorders objects of scorn, ridicule, fear, and hatred" (*Lunatic to patient* 407). A second transition and an important focus of this thesis began to take shape around the 1970s and on the heels of important human rights victories as well as a move toward deinstitutionalization. Reaume notes the importance of changing terminology as well as organizing and publishing as significant influences in how people with mental disorders saw themselves and he notes the foundational elements of the Mental Patients Liberation Project (416). "During the early 1970s", writes Reaume, "groups spread to California, New York, and Boston, which were primarily antipsychiatry in outlook, opposed to forced treatment including forced drugging, shock treatment and involuntary committal" (416). Finally, the present mental health system is the subject of analysis and is interpreted as a dynamic system through which

people access and provide services as well as a historical subject through which madness has been interpreted and through which authority has been established.

When Bell Canada announced that Olympian Clara Hughes would be front and centre in their *Let's Talk* campaign, madness entered the public realm, in a big way, kicked off with Clara's Big Ride across Canada (Bell Canada). Among many other things, the talk here is about both movement and identity. The movement, as I have come to understand and describe it through this thesis, is moving away from esoteric allusions pointing toward madness and asylums and toward a socially defined, socially prescribed form of mental illness. The allusions to that other kind of madness still exist, in literature and film especially, but mental health has effectively crossed the room to avoid such associations. The "talk" has moved even further away from its origins such that "mental unwellness" and "mental health" take up increasingly wider spaces in the public realm and in academic literature. Before being entirely swept up in today's mediated depictions of mental illness in which social inclusivity relies on the marketing of a particular mad person (such as Hughes or Howie Mandell in Bell's *Let's Talk*), it is worth looking at the process of medicalization and aestheticization through which such polished and presentable examples are presented. It should be noted that the coming out of Clara Hughes and other highly visible people is tremendously courageous and has clearly benefited many people who may have felt isolated with mental illness diagnosis. The flurry of activity around the industry's new shop window also presents an opportunity for critical analyses of the history, dynamics and processes of the mental health industry.

Such an analysis opens up subtle forms of regulating, or governing, practices and negotiations within the mental health system. The interviews were analyzed with a view toward the social organization of participants in the present mental health system within these contextual

and conceptual paradigms. Consumers and survivors described a diagnostic process that gets under the skin and contributes to past, present and future perspectives of self. The questions were directed toward social organization through and sometimes against the system and toward self-reflection and introspection. Almost all of the interview participants who were identified in the consumer/survivor group described being acutely aware of how they were perceived by others based on their presentation and/or on their mental health diagnosis. They were surprisingly unaffected by the terms used to categorize them as consumers/survivors. The people who were identified as stakeholders and caregivers situated themselves more or less critically aligned to the diagnostic processes and protocols of their respective professions. In more intimate and personal settings, often in the home, caregivers discussed the contradictions and necessity of the diagnostic process.

In *Technologies of the Self: A Seminar with Michel Foucault,* Foucault discusses "technologies of self, which permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality" (18). Foucault's analysis of institutional power had, by the time of his seminars at the University of Vermont in 1982, focused on micro-analyses of self in relation to power. "Throughout his works", writes Rux Martin, "Foucault had concerned himself largely with the technologies of power and domination, whereby the self has been objectified through scientific inquiry" (Introduction 3). He became "increasingly interested in how 'a human being turns him-or herself into a subject'" (Martin Introduction 3). Peter Miller and Nikolas Rose extend the analysis of forms of power, "power without a centre, or rather with multiple centres" and "productive of meanings, of interventions, of entities, of processes, of objects, of written

traces and of lives" in order to "point to ways in which contemporary forms of power were built on a premise of freedom, a type of regulated freedom that encouraged or required individuals to compare what they did, what they achieved, and what they were with what they could or should be" (Rose qtd. in Miller and Rose 9).

Each of these concepts—Foucault's technologies of the self, and Rose's analyses of contemporary governmentality—are foundational to the understanding of experiences from within and critical analyses of the present mental health system. The relationship and conduct of the self is an ongoing interpersonal and intrapersonal concern and was of primary interest to the Greeks. Foucault was interested in the evolution in Greek thought from caring for oneself, an intrapersonal and introspective reflection which extended to interpersonal conduct and knowing oneself, an ongoing conversation about oneself, undertaken with the aid of a mentor who would serve as a mirror. "The precept 'to be concerned with oneself' was, for the Greeks, one of the main principles of cities, one of the main rules for social and personal conduct and for the art of life. For us now this notion is rather obscure and faded" (Foucault "Technologies" 19). Foucault suggests the original Greek thought, care for thyself, was eventually absorbed into the Christian practices of avowing and disciplining the self, a self which is absorbed over time into other disciplining apparatuses. "[T]hrough these different practices—psychological, medical, penitential, educational—a certain idea or model of humanity was developed, and now this idea of man has become normative, self-evident, and is supposed to be universal" (Foucault 15). Psychiatry exists now somewhere between these two tensions of self-reflection and self-revelation. Some of the interview participants such as Simon, Quinn, and Cassie attempt to access disciplinary protocols such as hospitalization when necessary and alongside this negotiation is an ongoing fundamental intrapersonal life of private meanings and decisions.

Language, in the form of descriptors of symptoms, for example, is sometimes the first line of communication people pass as they enter into the system and the diagnostic process. The interview participants describe coming up against the limits of language which can reveal and distort and can directly affect how one self-describes and enters into dialogue with others.

Knowing oneself is an ongoing contemporary project. First revealed in late 20th century talk shows, that which was private has become public. Presently in Canada, the spokespeople for Bell's mental health campaign are celebrities such as athletes like Hughes, as noted above, and comedians like Howie Mandell and Mary Walsh. These are people whom we already recognize, but now we are invited to know them in their coming out about their mental illnesses. But whether they speak or should speak for people diagnosed with mental illness, the people who must navigate and access services from within an increasingly complex system is an ongoing (concern about voice and representation. In their most recent multi-million dollar *Let's Talk* campaign, Bell Canada aimed to "end the stigma" attached to mental illness. Another reading of the media and research blitz is that the campaign contributes to the stigma. Being identified as mentally ill leaves an open-ended diagnosis, one in which the audience is asked to participate in a silent self-appraisal. The problem, as Bell Canada's research team sees it, is access; they claim that more awareness, more research and more services are needed. In other words, it is not that there is a shortage of mental illness; it is that mental illness can now be found in places where it was not previously seen—across the broad Canadian population. What they miss are the embedded problems, tensions and contradictions in the system of treatment once one has accessed it and these are deep problems that this thesis examines.

Recent attacks on the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* (DSM-V) have also brought into question whether or not psychiatry should be the preeminent

means of treating mental illness. There are psychiatrists, however, who openly challenge the diagnostic process of the DSM-V. In a recent article by Emily Senger in *MacLean's*, Dr. Thomas Insel calls into question the practice of diagnosis based on symptoms. He says, "In the rest of medicine this would be equivalent to creating diagnostic systems based on the nature of chest pain or the quality of fever" (quoted in Senger). The ongoing debate over the DSM illuminates the concern that "the DSM-V adds new medical diagnosis [sic] which make it seem that nearly everyone is at risk for some mental- health disorder" (Senger). In another article, "Normal Behaviour or Mental Illness," Anne Kingston aptly calls "disruptive mood dysregulation disorder" a "newly minted condition." Allen Frances, a psychiatrist who worked on the DSM-IV, cautions doctors and others to avoid the DSM-V claiming that it will lead to "massive over diagnosis and harmful over-medication" (Kingston).

The mental health movement, which is an offspring of psychiatry in terms of its epistemology and social-political power, rather than being an alternative to the asylum and institution system extends the epistemologies and dominant framework by which we shape and respond to mental illness. In 2002 the Public Health Agency of Canada warned that "mental illnesses touch the lives of all Canadians" (*A Report on Mental Illness in Canada*). Since then the "one in five" statistic which was originally extracted from a 1996 study (Offord et al. qtd. in Public Health *A Report*) has become a brand in mental health talk. The report on mental illness aimed to "raise the profile of mental illness among government and non-government organizations, and the industry, education, workplace, and academic sectors" (Public Health *A Report*).The report has certainly been successful in setting a mandate to create space for dialogue about mental illness. The question remains whether this strategic marketing has done anything helpful. Mental illness, mental health and mental wellness services in Ontario today are delivered

from within a social and economic structure whose entry is a formal diagnostic process. Indeed, one of the goals of mental health campaigns is to direct people toward and through its system. This follows an undeniable common good philosophy, but as well, an undeniable economic logic. The point of interrogation, therefore is in the effects of the marketing of mental illness, mental health and mental wellness as products to be consumed and/or presented as currency at the gateway to services.

With diagnosis comes entry into the mental health system. Yet just when people are told that mental health intervention is necessary, they are left in a holding pattern. Tim Simboli Executive Director of the Canadian Mental Health Association's Ottawa branch, describes the current situation as "death by a thousand cuts" and says that "expanding into new areas and not properly funding old areas is a shell game" (*Ottawa Citizen*). Given the recent cuts to many mental health services it is an opportune time to measure and evaluate the tensions and interstices of psychiatry, its claim on mental illness, its rejection of the messy language of madness, and the off-shoring of its claimed expertise to the mental health industry.

1.2 Purpose and Directions

This thesis is concerned with the following questions: How do present day mental health consumers, survivors, stakeholders and caregivers organize and manage the access and delivery of services within Ontario's current mental health and psychiatric system? What are their actual experiences of the diagnostic and treatment processes? How does the present mental health system reflect historical ideas of madness and lunacy? To address these questions, the social history and organization of madness or mental illness is the focus of this study. I address the questions through both social historical and critical ethnographic methods (analysis of archives,

texts, interview transcriptions) and with the framework provided by Foucault and his commentators. This interdisciplinary thesis works across sociology and history, putting historical and contemporary mental health practices and discourses in critical conversation. The thesis contributes to the growing body of mental health literature by offering a space of reflection as to what is being written, by whom and to what ends about mental health and madness. It challenges the domain of mental health literacy and opens a new space onto a critical literacy about mental health and madness.

Mental health literacy is defined as "knowledge and beliefs about mental disorders; attitudes that promote help-seeking; knowledge of risk factors and causes, treatments and self-help and professional help available" (Jorm and Kelly 1). Jorm and Kelly's survey of peoples' understanding of mental illness showed that more people were likely to favour non-medical approaches in the presence of depression or schizophrenia. In fact, the study found that, "Many standard psychiatric treatments (antidepressants, antipsychotics, electroconvulsive therapy, admission to a psychiatric ward) were more often rated as more harmful than helpful, and some nonstandard treatments were rated highly (increased physical or social activity, relaxation and stress management, reading about people with similar problems)" (Jorm and Kelly 1). Despite this statement, the authors still concluded that mental health literacy needed to increase. In other words, the authors concluded that people need to be taught how to recognize and talk about mental illness and mental health concerns, and to know how to find professionals who could help. Today, mental health literacy and mental health campaigns are flourishing areas of research which rest on the assumption that mental illness is common and ubiquitous and that everyone should be talking about it. The education of the public, constant monitoring of this knowledge, as

well as the streaming of people toward mental health services are among the features of contemporary mental health literacy.

This thesis also works to provide other voices that need to be heard in the current mental health space. Thirty such voices of people (fifteen each of service providers and survivors) agreed to participate and are presented here and help to fortify and illuminate this work's social historical analysis. Each of the interview participants of the consumer/survivor group are introduced in the following section. As well, I describe my relationship to each person. It is important to acknowledge that participation in the interviews was individually motivated and participants were more or less interested in the overall thesis. All of the participants were directly or indirectly known to me and I had previous knowledge of them where they had very little knowledge of me. No one that I asked to participate in the interviews refused to take part.

The participants in these interviews (with pseudonyms) are: Christopher, Cassie, Brent, Pete, Holly, Leo, Quinn, Marcy, Jane, Steven, Simon, Brian, Sam, Patrick and Laura, all of whom have experienced the mental health system in quite different ways. We also have the honour of hearing from Maggie, Mischa, Sean, Dave, Sally, Layla, Jack, Collin, Kelly, Julie, Paddy, Sophie, Rhonda, Tim and Dannie, all of whom work or have worked or provide care within the mental health/mental illness system in Ontario. There are many who outright reject the consumer label, and many who take the entire psychiatric industry to task for its abuses and its fuzzy epistemological claims. The experiences of each of these people, from both within and outside the system, are an integral part of the analysis presented in this thesis. The interviews make visible the obstacles to various types of services, what comes to be described as relief, as well as the pathways that weave through an elaborate system of mental health/mental illness services.

To summarize the arguments and aims made in this introduction, this critical social history examines the experiences, treatments and meanings of mental health and madness in Ontario from multiple perspectives in order that new ways of knowing madness, through critical ethnography, can contribute to literature on mental health and madness. Some of the pivotal moments, along with a few of the most influential people and policies in the wider Ontario context are brought into focus to understand one of the most pivotal periods of social reform at the end of the nineteenth and early twentieth century. Local social histories of Sudbury, Ontario, the site of the ethnographic study and the place of the interviews, are interwoven with an analysis of wider social reform. The thesis brings the experiences, voices, and stories of people together with the social, political and historical contexts within which they are called, treated and seen as mad.

1.3 Foucault's Legacy

The texts that govern and underpin the mental health industry and the voices and experiences of those who now live within it have been shaped by historical imbalances, primarily of voice, but also of self-claimed expertise. In this particular time of rapidly growing information technologies and media saturation, something peculiar and important is going on in mad talk.

Analyses of post-asylum social organizing require a post-asylum understanding of psychiatric power. In Foucauldian terms this looks like a critical analysis of everyday techniques and processes through which power manifests as well as the genealogies of the subjects of psychiatric power. Foucault's analyses called for a re-ranking of "subjugated" or disqualified knowledges (*Power/Knowledge* 81). Through the knowledges of subjects, of "the psychiatric patient, of the ill person, of the nurse, of the doctor" a more workable dynamic of power is

disclosed (*Power/Knowledge* 82). This thesis makes visible the day-to-day lives of people considered mad. The system through which the mad presently make their way is considered through pivotal historical periods of its formation from asylums to community mental health.

The perspectives of psychiatric survivors and consumers are included. The perspectives of stakeholders and caregivers of the mental health delivery system are included. These terms, sometimes ambiguous and sometimes contentious, are the terms used within the mental health industry. The independent histories of the psychiatric survivor movement and the psychiatric consumer movement are not undertaken in this thesis. MindFreedom, an international non-profit organization marks one of the distinctions of survivor groups—they generally oppose and criticize intervention and they generally do not accept funding from sources such as governments, pharmaceutical companies or religious organizations. (MindFreedom).

The discourse of madness has rarely allowed for the voice of the madman or madwoman except to enforce a persistent gesture toward the not mad, which is increasingly understood in mental health literature as mental wellness. This is an important aspect of this thesis as I weave together previously unheard voices with an interrogation of the social, historical and political conditions in which they are heard. While the psychiatric industry continues to name and claim madness as its special domain, more inclusive approaches add to the knowledge about madness and challenge a historical imbalance. The conditions upon which these imbalances came to be are traced historically in this thesis through examination of specific techniques used to organize, control and maintain surveillance within the vast network of psychiatric and mental health services. I focus on madness in its current state and describe "the transformations themselves" (Foucault, *The Order of Things* xiii). For example, I discuss the work of John Langmuir, a late nineteenth century Inspector of asylums and social reformer, to make visible the interplay of

politics and ideology at the foundation of Canadian asylum history within the context of Foucault's idea of "conditions that dominate and even overwhelm" as well as "the rules that come into play in the very existence of such discourse" (*The Order of Things* xiv).

Psychiatry has at its foundation an epistemological period wherein the voice of the patient was absent because it was not thought possible that this voice or experience would add anything to the knowledge about madness. In fact, those receiving services, at least in the context within which this thesis exists, are generally understood *only* in the context of predetermined ways of assessing and talking about mental illness. Toward the end of considering how madness might otherwise be discussed and how experiences of mad people might otherwise be considered outside of the clinic, away from the mental health services industry, this thesis adds a piece to the story. This piece includes active contemporary participants—those receiving services from the mental health industry and those dispensing services. I enter this system critically, perhaps more critically than many of the interview participants, and I do not speak for them.

I also regard this system through a critical and historical lens involving my own history of working in institutions. The concepts of opposing indicators such as rational and irrational thought laid the groundwork for what ultimately became, in the madhouse, ways of seeing and saying, or as Foucault calls it the "glance" (*Birth of the Clinic* 4). His observations in *The Order of Things*, were that we had entered, through the "rationalism" of the seventeenth century, which marked "the disappearance of the old superstitious or magical beliefs and the entry of nature," we had entered, "at long last, into the scientific order" (54). What followed from here, Foucault argues, was a move away from looking for categorical sameness, away from an epistemology that would result in an ordering of things into hierarchically organized, named and numbered things, and towards a process of "discriminating," for which the primary function is the

"fundamental investigation of difference" (*The Order of Things* 55). The separation into categories and spaces is reflected, as many of the interview participants in this thesis make clear, through language and policy.

As Dowbiggin makes clear, psychiatry, psychiatrists, journals and governing bodies acknowledged early on that the power they had was to be shortly usurped by government intervention wherein boards were created "that quickly began to treat the asylum as simply one institution in a much larger network of public welfare facilities which included prisons, almshouses, and orphanages" (*Keeping America Sane* 9). In the late nineteenth century psychiatry and psychiatrists were presented with a challenge from the emerging science of neurology. Neurologists such as Edward C. Spitzka and William A. Hammond were outspokenly critical of psychiatric methods: "From the neurologists' point of view, asylums were valuable primarily for supplying physicians with plenty of clinical material to study" (Dowbiggin 11).

A wide and comprehensive psychiatric history is that assembled by Thomas Workman. Speaking about the history of the care of those deemed mad or insane in Canada, T. J. W. Burgess, prefaces his 1905 article in the *Montreal Medical Journal* by acknowledging the prestige of having been invited to the position of President of the Association ("Insane" 399). He then describes psychiatric history beginning with the establishment of the first Hotel Dieu of Quebec in 1639 (Burgess "Insane" 400). Burgess describes the treatment of the insane which included practices such as chaining those who were deemed insane by authority of "any two justices of the peace" (Burgess "Insane" 89). He presents a comprehensive history of Canadian institutions, beginning with the Hotel Dieu of Quebec founded in 1639 by Duchess D'Aiguillon "for the care of indigent, patients, the crippled and idiots" (Burgess 88). The organization of the "insane" both "curable" and "incurable," as well as the conflation of criminality with madness,

will be discussed further in Chapter Three. For the purpose of this discussion, the mad, however categorized for public consumption, have historically been people around whom a great deal of mystery and fear has been propagated, especially as institutions grew to insulate the process of diagnosis and treatment, much of which was experimental.

In *Discipline and Punish,* Foucault says, "I would like to write the history of this prison, with all the political investments of the body that it gathers together in its closed architecture. Why? Simply because I am interested in the past? No, if one means by that writing a history of the past in terms of the present. Yes, if one means writing the history of the present" (31). In disassembling the political structure, the laws, the mechanisms of control, and even in analyzing the "revolts against model prisons, tranquilizers, isolation, the medical or educational services," Foucault aims to understand the modern technologies of power (30). What were these revolts against if not against the "merely material" (30)? They were movements "about the body and material things" (30). How did we get here and what will the people who organize themselves bring to this history? In *The Order of Things,* Foucault recounts his experience of reading a passage in which Borges describes the categorization used in a "certain Chinese encyclopedia" (xv). Outside of the vicarious pleasure of reading the passage with Foucault, what is demonstrated is Foucault's catching on to the rigidity of his own thought. He is startled and amused to find "all the familiar landmarks of my thought—*our* thought, the thought that bears the stamp of our age and our geography—breaking up all the ordered surfaces and all the planes with which we are accustomed to tame the wild profusion of existing things" (*The Order of Things* xv).

What was startling to Foucault is that the passage referred to comes out of Chinese culture, a culture that exists in traditional Western imagery as "the most meticulous, the most

rigidly ordered, the one most deaf to temporal events;" a culture for which, "Even its writing does not reproduce the fugitive flight of the voice in horizontal lines; it erects in motionless and still-recognizable images of things themselves in vertical columns" (*The Order of Things* xix). This admits a kind of possibility of disruption of even the most imposing monoliths, such as the history of the present state of the mental health and psychiatric industry purports to be. Indeed, this imposing system is experienced as both all-powerful and as a source of relief. Movements, in the wider sense of social movements, can be understood and interpreted through local ways of organizing, negotiating, strategizing and resisting.

To understand the causes of changes in thought, practice and in discourse about madness, to place current ideas and treatments of madness in historical context, and to observe the small and numerous changes in this vast history, required choices as to historical period, place, texts and people interviewed. The focus of this thesis research, therefore, begins in the present, with people living and working within the system in a Northern Ontario city. I then look back to the mid-nineteenth century institutional era of Ontario through Government documents such as census data and annual reports. The past forty years, a period that coincides with the experiences of those who were interviewed, have seen rapid changes and much of the analysis of this transformation is included in the last two chapters. I will show that multiple influences and forces have converged to allow for the appearance of the mental health industry that exists in Ontario today.

Among the most fascinating features of this thesis has been the rapidity with which the field of mental health and psychiatry are changing. New ways of describing and self-describing madness continue to emerge. Mad talk across Canada is flourishing as a way to critique, resist and challenge the voice of psychiatry. Insiders and outsiders who self-identify as resisters,

survivors and critics as well as industry insiders are bringing penetrating light to the dim corridors of the past. The dimness is in the reasoning behind some of the treatments, practices and theories.

Irit Shimrat identifies as someone who "hate(s) psychiatry as much as anyone" ("Two Essays"). Shimrat promotes the telling of stories of resistance as well as the promotion of better alternatives, some of which are as simple as sharing kindness and spending time with someone in distress ("Two Essays"). She has also been active in helping to provide a forum for telling stories of psychiatric "treatment" (her quotations), being the editor of "Phoenix Rising: The Voice of the Psychiatrized" (which has since been posted online and is an important resource of the Psychiatric Survivors Archives, Toronto) in 1986 and publishing a book called *Call Me Crazy: Stories from the Mad Movement* (Shimrat "Two Essays").

The critics range in experience from psychiatric survivors (experts on their own experiences) to neuroscientists (experts on the brain). Shimrat, Don Weitz and many others identify as psychiatric survivors—people who have lived to tell about the effects of psychiatry's long history of experimentation. The history of consumers and survivors is a shorter and more recent history than that of asylum and alienist history. Nonetheless Shimrat's *Call Me Crazy*, Weitz's "Call Me Antispychiatry Activist-Not Consumer", Reaume's *Remembrance of Patients Past* and Barbara Everett's *A Fragile Revolution* interrupt histories about psychiatric asylums and treatments to add important perspectives of people from within the mental health system.

In *Great and Desperate Cures: The Rise and Decline of Psychosurgery and Other Radical Treatments for Mental Illness,* neuroscientist Elliot S. Valenstein describes the period of time "between 1948 and 1952," when "tens of thousands of thousands of mutilating brain operations were performed on mentally ill men and women in countries around the world" and

where [in the United States] under the name of 'lobotomy' the procedure was widely used on patients from all walks of life" (3). Called collectively "psychosurgery" these brutal operations were performed by "insert[ing] into the brain any of various instruments—some resembling an apple corer, a butter spreader, or an ice pick—and, often without being able to see what he was cutting" and thereby "destroy[ing] parts of the brain". (Valenstein 3). There can be no doubt that the surgeries were performed in the callous spirit of experimentalism; these were not brains considered personal and valuable, but rather organs upon which psychiatry could test various theories. The introduction of psychotropic drugs followed on the heels of this spirit of experimentalism. Heavy sedatives such as chlorpromazine "provided a simple and inexpensive alternative" and paved the way for psychiatry to move away from psychosurgeries, "leaving in their wake many seriously brain-damaged people" (Valenstein 3).

Linda Andre's introduces her book, *Doctors of Deception*: *What They Don't Want You To Know About Shock Treatment* with a few brief words on terminology. She "would have preferred" she writes, to surround with quotation marks every use of the terms mental health, mental illness and mentally ill and she avoids labels such as psychiatric survivor, client, and consumer, choosing instead to use the term mental patient (Introduction). Andre wishes "to avoid granting even subliminal credibility to the medical model" (Introduction). I have many of the same concerns and my concerns are extended to the use of these terms in promoting a false sense of autonomy, a disrupted sense of self, and often under or non-consensual inclusion in the economically driven mental health industry.

"Imagine", Andre asks her readers" you wake up tomorrow with your past missing" and "worse, you find that your daily memory and mental abilities aren't what they were before" and "you are somehow slower, less sharp, less able to resume your former work" (1). It is a horror to

imagine and yet, as Andre writes, "electroshock is the only one of the drastic somatic 'treatments' developed in the eugenics era that is still in use today and the only one whose very name doesn't evoke derision or horror" (42). Indeed, when I began my research and needed access to local hospital libraries, a friend offered to arrange for me to witness a performance of shock treatment, which he called ECT.

As histories and personal accounts of psychiatry are gaining some currency and can no longer be dismissed as conspiracy theories. Canada has a long history of psychiatric treatments that are linked to social and psychological experimentation. Anne Collins, a journalist writes about the career of Dr. Ewen Cameron and the devastating effects of his experimental treatments in psychic driving. Collins' work, *In the Sleep Room: The Story of the CIA Brainwashing Experiments in Canada*, fits into a body of literature produced in the 1970s and 1980s that focus on CIA experiments, with code names such as MKULTRA. If it were not for outstanding class action lawsuits naming Cameron, Oakridge, the CIA, and Huronia, these accounts could easily remain in the conspiracy theory category, just too hard to believe, especially, as Collins notes, when, "nobody except other fringe-dwellers pays attention to the fringes" (Collins 4). Online organizations such as MindFreedom, Mad in America, and The Antipsychiatry Coalition present experiences of psychiatric treatment, for example. As well, people taking medication can access a number of websites to discuss with others the effects of psychotropic medications and their experiences of mental illness and diagnoses. Each of the psychiatrists interviewed for this thesis spoke of the need for electroshock treatment in some cases, and one psychiatrist spoke candidly about the links between military and psychiatric training in the Cold War era.

In psychiatry, many roads lead eventually to diagnosis. The diagnostic process is reflected in the words of another one of the thesis participants (Christopher) who eloquently

narrated a conversation with his psychiatrist. Christopher recalls his psychiatrist telling him, "You know, Christopher if you were a rock star, if you were like Elton John, David Bowie, you'd make it, but because you're a poet and because it's Sudbury, they don't comprehend and I kind of told him the same thing myself" (Christopher). So what is a man out of time (or place) to do? For Christopher, a self-described poet and mystic, who identifies also as "Hummingbird," an awareness of the anachronism seems to help. There is lightness about Hummingbird, and every spring, no matter how cruel the winter abuses, he emerges on the scene as Stravinsky's Fire Bird. Hummingbird rejects the mad label he has been given; he rejects it at its pathological roots, and perhaps there is also in his rejection at least a gesture toward the iatrogenic power of the categorization process of the DSM-V.

Christopher is rejecting a multiplicity of forms of power: the power of the DSM; his discussions with doctors; the authority of the hospital to allow him to enter and to leave; and the narrow idea of himself as constructed by the community in which he must live. In *Power/Knowledge,* Foucault writes, "power, if we do not take too distant a view of it, is not that which makes the difference between those who exclusively possess it and retain it, and those who do not have it and submit to it. Power must be analyzed as something which circulates, or rather as something which only functions in the form of a chain" (98). In this sense, both Gilles Deleuze and Foucault have wrestled with Friedrich Nietzsche's idea of genealogy of power. Deleuze describes, in *Nietzsche & Philosophy,* how phenomena take on power according to the various networks they insert themselves within: "This is what the will to power is; the genealogical element of force, both differential and genetic" (50). Foucault uses the genealogical method in *Discipline and Punish,* seeing it as an approach that would witness the power of the penal system at its very birth. He writes:

> We have, then, a public execution and a time-table. They do not punish the same crimes or the same type of delinquent. But they each define a certain penal style. Less than a century separates them. It was a time when, in Europe and in the United States, the entire economy of punishment was redistributed. (7)

Foucault then begins to speculate about the disappearance of certain disciplinary mechanisms and the appearance of others. This is power hiding and reshaping itself, with punishment becoming "the most hidden part of the penal system" (9). Foucault reminds us throughout *Discipline and Punish* that the object of the body remains the site of collective and multiple forces. As the interview participants in this thesis research make clear, the site of the body remains the site of analysis and observation. The new normal, at least according to psychiatric assessment, is measured against deviations in behaviour. In some way and by someone, each of the participants who identify, even if just for the purpose of this study, as survivors or consumers of mental health services, have been assessed as falling inside of or outside of medically-, culturally- and socially-abstracted ideas of normal that are located in the present mental health discourses as "well."

The interviews represent the experiences and reflections of thirty people who were selected for their expertise and experiences of the mental health system. These are people who have been described as mad, fag, retard, fucking idiot, schizophrenic, manic depressive and mentally ill. These are people who have listened to, witnessed and provided care and services in the context of the present mental health system. Some of the participants' responses to open-ended questions have been left uninterrupted to capture their unimpeded interpretations of their experiences; the experience of what is sometimes called mental illness can include mystical and poetic interpretations of reality not easily captured in even open-ended interviews. The rich

stories of each participant will continue to contribute to analysis of the present day mental health system, in tandem with analyses of its social historical foundations. In essence, I have asked what are the historical roots of the mental health system? How is this experienced in the present and from within the system? Beyond this, as ideas about mental health as a political mandate coalesce with real threats to the full spectrum of being, I ask, what is at the horizon of ways of knowing that madness can reveal? The interview participants guided by the interview questions have articulated experiences of people reflecting on relatively recent psychiatric history. In the next chapter, a few of the themes are explored and analyzed further for what they have to say about madness.

The terms that have been used historically as well as those that are used in the present do little to express the unique experiences with thoughts and emotions that every human being encounters from birth to death—in fact they limit the possibilities of expressing these. Some of the terms I use here, such as imbecile and lunatic make just this point. Many terms that would otherwise cause offense are used here in the spirit of claiming the full spectrum of language that has been used to define people historically separated or institutionalized. Terms that are used often to refer to the interview participants are explained in more detail.

1.4 Madness: Seeing and Saying

The new normal, represented in Sonia Roy's depiction which accompanies the article of the same name by Rachel Giese is the product of a decades old inculcation of the mental health message, promoted by the mental health movement and meant to replace the old image of madness and thereby reduce the stigma, created incidentally by the same system. We are mostly quite familiar with the inhumane treatment of mad people. The new face of mental health

promoted by the Bell *Let's Talk* campaign is meant to get those images out of our heads and to re-think madness as mental health. It is one of many mental health campaigns meant to get people talking about their experiences with mental illness. Roy's glossy image could be a starting point for this conversation; on one side of the page is the asylum madman, dangerous and doomed and on the other is the new mental health patient consumer full of hope and, as the image promises sunshine and butterflies. The messages of the mental health movement stand in contrast to its very real asylum history and, in the present, open up the possibility of a different type of talk, one that is less willing to accept the entitled authority of the psychiatric industry and even a bit suspicious of the growing imperative of mental health.

People who access or who have accessed services from either hospitals or community mental health services identify in lots of different ways for lots of different reasons. Psychiatric survivors tend to identify *themselves* as such and the term is significant and meaningful, pointing to a united or commonly experienced sense of outrage against psychiatric abuses and intrusions. Other people who access or are directed to mental health services are referred to as consumers, meant to connote a more mutually inclusive treatment protocol and in line with a delivery model which promotes a view of the consumer as an informed client. There also exist alternative mental health services and mad coalitions which can stand at the periphery, at the centre, or in opposition to the psychiatric system. These offer the support, encouragement, and experience of people who are called peers or who have lived experience of mental illness as well as spaces and programs meant to attend to the specific needs and purposes of people who have a mental health diagnosis. I have used the term madness throughout this thesis because invoking the word does at least two things; madness encompasses a broader range of social and cultural experiences of being human—as a complement to this goal, it erases the false chasm between reasonable and

unreasonable, sane and insane, mentally well and mentally ill. From the perspective of the psychiatric survivor and consumer movement, mad language is reclaimed as a position of shared experience and toward the aim of archiving institutional memory.

Don Weitz describes himself as an antipsychiatry activist. He writes and speaks about psychiatric abuses such as psychosurgery, electroshock treatment, as well labels such as schizophrenic (Weitz). Weitz is not imagining such mad abuses. Indeed, a class action lawsuit has been filed by Toronto law firm Rochon Genova on behalf of a group of patients who were subjected to physical and psychological torture as recently as the 1960s and late 1970s. The suit names Dr. Elliott Thompson Barker and his human experimentation programs, namely "The Insane Criminal as Therapist" (1968), an experiment in which one patient would be selected to prescribe for other patients medications and practices administered for a day. Other experimental programs were "Buber Behind Bars" (1968), "Defensive Disruptive Therapy" (1969), "The Total Encounter Capsule" (1977), and "LSD in a Coercive Milieu Therapy Program" (1977) (Oakridge Class Action 7). The results of these experiments were published in the *Canadian Psychiatric Association Journal* between 1967 and 1977; they were retrieved for the purposes of the lawsuit.

Geoffrey Reaume begins his description of the organizing of the annual Psychiatric Survivor Pride Day (it was going to be called Crazy Day) with a discussion of the use of the word pride ("A History" 2). During the organization of the first event, meant to "fight stereotypes" as well as "the prejudice of local rate-payer groups in Parkdale who opposed housing for discharged psychiatric patients", community insiders and outsiders wondered what they had to be proud about ("A History" 2). As well, some in the organizing group were wary of the term "Pride Day" and its association with gay Pride Day, others like the term for the same reason and its potential for "link[ing] up with other marginalized groups" ("A History" 2).

Beyond negotiations of the image and message the organizers wanted to convey, the group organized around the word "survivor". As Reaume recalls:

> The word "survivor" was chosen to show that there was much pride in our history of surviving discrimination and abuse inside and outside the psychiatric system, in advocating for our rights and in our personal and collective accomplishments—that psychiatric survivors are much more than a diagnostic label. ("A History" 2)

Mental health *consumer* as a term, is aligned with the organizing and advocacy work of the psychiatric survivor movement, at least in Canada, and at least according to some accounts. In a report for the Black Creek Community Health Centre, Onar Usar describes the goals of "advocacy, choice, peer support, self-help with respect to mental health consumerism and those who access services because they have come to see themselves as mentally ill or because they believe they can achieve mental health (or wellness) only through recourse to the mental health system (Introduction 1). Mad culture exists to some degree in the multitude of mad blogs and websites, published biographies, music and film. The culture has taken on new modes of discourse, and new forms of power, within the present information and technological society. As Collin Koopman puts it, "We do not like to think of ourselves as bits and bytes. But if we don't, we leave it for others to do it for us" (Koopman 1). Koopman introduces "a new kind of person: the informational person" (1). A Foucauldian theorist, Koopman describes technologies of information such as the implementation of fingerprinting and the registration of births (Koopman). People who enter the mental health system are especially vulnerable to such tracking and surveillance technologies. Ironically the very tools used to assess deficits in daily functioning justify ongoing surveillance and reporting of such mundane activities as personal hygiene, socializing, and goal setting. We are witnessing a new way of speaking about mental

health and madness. The former threatens to subsume the voice of the latter while ostensibly allowing it to speak.

All of the participants in this study speak from within the medical model of mental illness, some willingly, some out of necessity, and some speak of their separation from it. Some of them have accessed mental health services and some have been given a diagnosis. Cassie, Simon, Brent, and Christopher described the tensions in needing things from the hospital system, but also going through periods of resistance. Compliance often seemed to be the key to getting what was needed: a bed for Quinn, sleep for Simon, and freedom for Cassie. This compliance seems to render the consumer of services back to the blurry role of patient-consumer: speak, but not too loudly and not too long. The fifteen participants in the service provider and stakeholder group were more critical, and they spoke with the authority to criticize. Mental health and mental illness talk have increased dramatically in the past several years and these new locations and images of madness are presented in the contemporary context in this thesis. This presentation opens up a new set of questions relating to how we see and speak about madness. The following section is a synthesis of what I was reading, hearing and seeing about mental illness and madness and what others were seeing and saying as well. I will describe my initial interest and insider observations of the mental health system and the ways in which these eventually coalesced and invited the possibility of advancing the literature on mental health and madness.

1.5 A Brief Historical Standpoint: The “Troubled Persons Industry”

My initial interest in mental illness as a research topic came about through my work in the field of mental health and addictions. It was from this perspective that I began to be interested in the inner mechanisms of what was becoming a new mental health industry. My

reflections on working in group homes provided a place from which to consider what Nikolas Rose and Peter Miller describe as a history of "making up" people (*Governing the Present* 9). I worked in group homes for adolescents in the mid- to late1980s, and then I worked in the field of mental health and addiction which, during the 1990s, saw a change in services that increased the mandate of addiction treatment centres to include people with concurrent and/or co-occurring mental illness. The changes in terminology were dizzying; they were always accompanied by new policies aimed ostensibly at inclusion, but there was also a downloading responsibility from specialized professional care into the ever-increasing layers of what was becoming a mental health service industry.

Within this period there was an increase in the medicalization of addiction and the creation of new categories and classifications of mental illnesses, such as substance-related disorder (American Psychological Association 191). The World Health Organization has also made attempts to settle on descriptive terms for drug use, addiction, and alcoholism, the latter being considered a disease in the nineteenth century and reintroduced to the medical literature around 1939 by way of the self-help organization *Alcoholics Anonymous* (World Health Organization 12). These terms, clinical in nature, were taking hold of the everyday lexicon of what was unfolding as an industry of mental illness and addictions. As a counselor, I attended workshops and conferences and read the literature on best practices for women and for people with concurrent disorders. Between the mid-1990s and the beginning of the twenty-first century, the field of mental health and addictions continued to change rapidly with professionalization of services, collaboration of funding and services, the increase of more complex diagnoses, and, most notably, the increase of harm reduction strategies, which were all born out of best practices research and literature.

The people who are considered to be served by these understandings, diagnoses, and practices are often those of what Joseph Gusfield calls the "troubled person's industry" (*Constructing* 421). These are the people involved in the system of mental health and addictions. The participants' self-descriptors were often harsh and condemnatory, pointing toward an image not at all congruent with the tidy (and frequently updated) medical version of them described in the DSM. The disjuncture was intriguing and jarring, and it presented for me a set of interstices worthy of exploration and reflection. One of the most poignant of these self-described experiences came from a nurse who had become addicted to opiates, lost her job, entered street level addiction, and eventually opted for the harm reduction methadone program. While methadone therapy is an alternative put forth as less harmful, it is often described as if one is tied to a chemical leash, and people using methadone speak of living for the visit to the pharmacy. The joining of new terms such as "co-morbidity" and "concurrent disorder" sweep together the mad and the junkie, depositing them as one "consumer" into a newly emerging (and lucrative) system of pharmacology.

An article, "The New Normal," in the May 2013 issue of *The Walrus* is accompanied by an illustration (by Sonya Roy) of two opposing images: two men, or rather two images of the same man, face a centre line dividing the page. One man holds the leash of a pet spider (a tarantula no less) while his mirror image holds the leash of a pet butterfly (a monarch). The symbolism is obvious: the tarantula signifies danger, darkness and foreboding, while the butterfly suggests a transformation from the ugly caterpillar to the beautiful monarch, from bondage to freedom (although still, in this image at least, it is tethered and tamed).

The tarantula owner foregrounds a backlit gothic structure surrounded by bushes, which appear to be burning. Dark clouds on the horizon warn that something is about to happen. Black

raindrops fall directly onto the spider keeper's head. On the right of the page is a shiny glass and steel building, in front of which a man is standing under a warm yellow sun. This man, the butterfly keeper, is knee-deep in chemical compounds and equations, coloured capsules of medicine. The author of the story accompanying this illustration, Rachel Giese, tells of the gentrification of Toronto's West End. Giese describes her tour of the psychiatric hospital and provides a brief history of institutionalized psychiatric care in Ontario. She ends her piece with her observations of a small act of kindness bestowed upon an unruly (we can guess) psychiatric resident and her hopes for a changing society—a "revolution" (39). Roy's illustration, however, is a much more seductive and interesting invitation for reflection on the themes raised in Giese's article.

The Centre for Addiction and Mental Health "was formed in 1998 as a result of the merger of the Clarke Institute of Psychiatry, the Addiction Research Foundation, the Donwood Institute and Queen Street Mental Health Centre" (CAMH). Let alone the interesting separate historical trajectories of each institution that they combined to form the largest teaching and research hospital in the country is noteworthy. Also established in 1998, was the Canadian Alliance on Mental Illness and Mental Health (CAMIMH). CAMIMH claims to exist to "ensure that mental health is placed on the national agenda so that persons with a lived experience of mental illness and their families receive appropriate access to care and support" ("About CAMIMH"). According to CAMIMH, "Nearly six million, or 1 in 5 Canadians (20% of the population) today are likely to experience a diagnosable mental illness; 3% of Canadians are likely to have to live with a serious mental illness" (CAMIMH "Get Involved"). On first read, one might see this as a positive move that is aimed toward the removal of stigma historically associated with mental illness or madness. Yet one must wonder at the relatively uncritical

acceptance of a theory that proclaims that a substantial proportion (one fifth!) of the population is unwell.

CAMIMH describes itself as a non-profit volunteer run organization. Among its sponsors are Rx and D (a pharmaceutical research company), the Bell *Let's Talk* campaign, the Mental Health Commission of Canada, Lundbeck (a pharmaceutical products company), and a public relations company (CAMIMH "Sponsors"). In teaming up with corporate partner Bell, CAMIMH, the self- appointed new voice of mental health, proclaims that there is a crisis in Canada. The associated research centres and pharmaceutical companies, it reasons, can only stand to benefit from such a crisis. There is a great deal of movement going on in the mental illness/mental health industry. So what does all this movement mean for the estimated six million Canadians for whom this system claims to exist? Where will the ebbs and flows of this industry lead us next?

The historically silenced and inchoate forms of the mad are invited to participate in a medically, socially and corporately structured conversation about mental illness and mental health. Those accessing the mental health system have been having conversations all along—on blogs and in biographies, in hospitals and psychiatrists' waiting rooms. The mad and mentally ill consumers and survivors have been talking, organizing, mobilizing and critiquing psychiatric treatments and abuses. There are other ways of thinking about and talking about madness than those offered by a system that is in the business of managing the same symptoms it is also relied on to identify. The following section will contextualize the present state of the mental health system, noting the inclusion and formulation of recent entities as well as new modes of everyday discourse about mental illness.

The discourse surrounding mental illness is changing rapidly. Specific periods of time have seen significantly increased momentum in changes in delivery service models as well as ways of labeling what is emerging as mental illness, which is quite distinct from madness. It is almost as if we are witnessing, since the 1980s, a new use and a new space for mental illness and mental health talk. These transformations form the basis of the historical analyses and interviews in Chapter Three, Chapter Four and Chapter Five. The following section sets the stage upon which much of the thesis unfolded. It describes some of the people, places, and events that have culminated in a new mental health landscape of bricks and mortar, ideas and ideologies, and virtual spaces.

1.6 Locating the Mental Health Movement

> The fact is that every time psychiatrists formulate a new rule of mental health, they create a new class of mentally sick individuals. (Szasz, *The Manufacture of Madness* Introduction xxxi)

The relatively new mental health movement has changed the landscape for many people, including the interview participants. In this piece, I briefly discuss the relevance for each of the interview participants and their respective "places" in the mental health industry. The mental health movement comes out of the Mental Hygiene Movement of post-war Canada and the United States. "The Mental Hygiene Movement," writes Dr. Adolph Meyer in 1911, "owes its origins to the realization that the problems of mental health and the prevention of misfits and disease must be attacked beyond the walls of the hospitals which to-day deal with mental defect and mental disease" (632). The mental health movement in the present day is at a crossroads as everywhere it seems people are coming out as a little or a lot mad. In a time of heightened surveillance, selfies and Facebook, there are no dark corners in which to hide. As mental illness

and madness are erased from the conversation, it is a crucial time to re-examine the state and experiences of madness and its social history.

Szasz describes the mental health movement as a phenomenon that replaced one form of social regulation for another, and which arguably resulted in "the substitution of a medical mass-movement for a religious one, the persecution of mental patients replacing the persecution of heretics" (*The Manufacture of Madness* Introduction xx). Szasz began his work on comparative forms of social regulation with *The Myth of Mental Illness*, published in 1961. In an article describing Szasz, his life and his death, Szasz is quoted from a 1969 interview as saying, "When metaphor is mistaken for reality and is then used for social purposes then we have the makings of a myth" (quoted in *The Telegraph*). He continued, "I hold that the concepts of mental health and mental illness are mythological concepts, used strategically to advance some social interests and to retard others, much as national and religious myths have been used in the past" (quoted in *The Telegraph*). Szasz was convinced about the harmfulness of the concepts invoked by the mental health movement mainly because they left such little room for other interpretations of human behavior. Indeed, this was a common criticism in his work and an idea expanded upon in *The Manufacture of Madness*.

> Dissent from such ideologies is both conceptually difficult and personally hazardous. Ideologies couched in a salvational or therapeutic vocabulary are particularly resistant to criticism. Such belief systems command not only obedience to the truth, as revealed to priests or physicians, but also define skepticism as heresy or madness. (Szasz *The Manufacture of Madness* 133)

Whereas Szasz claims that there is no such thing as mental illness and that the symptoms of behavior mistaken for mental illness occur through the same process of control used by the

religious imperative, R.D. Laing argues that psychiatry's use of intrusive treatments and the paucity of human interaction in these were the main therapeutic errors in psychiatry. Laing, a Glasgow University and army-trained psychiatrist, approached the practice of psychiatry by acknowledging the importance of the "patient" (Laingian Society). Laing felt that involuntary confinement, the prolonged use of drugs, and the treatment of psychiatric patients as anything less than equal human beings was harmful and unhelpful. Laing, like Szasz, rejected the anti-psychiatry label some wanted to attach to him. He agreed that "by and large psychiatry functions to exclude and repress those elements society wants excluded and repressed" (*Wisdom, Madness and Folly* 9). Whereas Szasz argues that an industry grew around an established practice of social regulation and indeed eventually replaced one form for another, Laing claims, from his position within the psychiatric industry, that a more therapeutic approach would benefit the patient. Laing's approach echoes similar historical reforms with its seemingly humanitarian emphasis on how the patient *should* be treated but it fails to engage in a more critical analysis of the established order or *raison d'être* of the psychiatric hospital. To quote Foucault, in his observation of the limitations of reformers Pinel, Tuke and Wagnitz: "It was in these spaces of confinement that Pinel and the psychiatry of the nineteenth century met the mad, and—lest we forget—it was there too that they allowed them to remain, while claiming to be their liberators" (*History of Madness* 47).

When psychiatry began to experience criticism from within its own ranks, Laing and his hippy, down-to-earth approaches must have seemed a threat indeed. The threat was tamed, however, when Laing saw the opportunity to collaborate with colleagues and direct his moral observations into research. The army training of Laing and of many pre- and post-war psychiatrists culminated in continuation of the practice of experimenting on human beings and

observing their reactions to social and environmental manipulations. In social interactive approaches such as Laing's "Rumpus Room," patients with schizophrenia were observed while Laing and his colleagues theorized as to any improvement or deterioration in the social behavior of those selected to participate in this social experiment (Beveridge 200). The description of the Rumpus Room in Beveridge's *A Portrait of the Psychiatrist as a Young Man*, a book about Laing's early work, is aided by published and unpublished insights written by Laing. Beveridge speculates that Laing was taken under the wing of influential colleagues in part due to his "intellectual precocity" (200). Indeed, in this period, a trait such as curiosity would be rewarded with research funding and inclusion in collaborative projects. The "Rumpus Room" was just such a project. In notes, the behaviour and reactions of a schizophrenic patient are described by Laing and by nurses. The patient is presented through the lens of Laing who, being in the position to choose his frame of observation in this historical moment and place, looks with compassion as well as curiosity. This is evident in many biographical accounts of Laing's life. There is, though, a voyeuristic fascination of the narrator of this image. Missing is the perspective of the patient as these have been reduced to voiceless phantoms in the experiment. Their words, when they do speak, are always interpreted by Laing.

Laing's psychosocial experiments at Gartnavel coincided with a significant move in psychiatry. The 1950s saw the introduction of psychotropic experimentation in psychiatry. The war had provided opportunities for human experimentation across the globe and continued, in Canada, at the Allen Memorial Institute in Montreal (Collins) and at the Oakridge Centre in Ontario (Rochon Geneva Law Firm). The 1950s were also a notable period of mobilization for those who identified as having personal experience of living with or having been diagnosed with mental illness. Canadians, such as Clarence Hincks, spoke publicly about their own experiences

with mental illness. Hincks, along with Dr. C. K. Clarke, established an outpatient clinic for psychiatric patients being discharged from the hospital, and in 1950 Hincks formed the Canadian Mental Health Association (CMHA), from the original Canadian National Committee for Mental Hygiene founded in 1918. Alongside more regulated organizations such as the CMHA, which claimed to help people with mental illness inside and outside of hospitals, more radicalized groups were emerging from the mental patients' liberation movement (Starkman 27).

Whatever the trajectory into the mental health system, the subjectivities available to those considered mentally ill are limited and limiting, often experienced as somehow incomplete and forward-striving toward success and measurable functionality. Movement, activism and participation in the system can come through the roles of compliant and autonomous consumer and/or survivor. The mad artist or *poète maudit* who perhaps romanticized in literature and film is now more likely to appear as dangerous and threatening, and the mad are over-represented as perpetrators of violent crimes. Success, as Brent (an interview participant) has experienced it, is being able to function outside of the hospital and being allowed to go home (Brent). Beginning with Hincks and, before him, Beers' accounts of their own experiences with mental illness in the early twentieth century, first hand or experiential perspectives began to be recognized. As Hincks, in Canada, began to use his own experiences in treating his patients, Beers, in the United States, had written his autobiography, *A Mind that Found Itself,* in 1908. The importance of what has come to be called "lived experience" was foundational to the early twentieth century Mental Hygiene Movement.

Global events have also shaped the trajectories of careers and experiences of psychiatry in particular, especially when psychiatry attached itself to wider social reform movements. Both the First and Second World Wars were influential in directing attention and funding toward

matters of social control and mind control respectively, with psychiatry establishing itself as the domain of the latter. Opportunities for training, research, collaboration, and networking abounded in the burgeoning Mental Hygiene Movement. In 1918, Ian Dowbiggin writes, "Fundraising was an immediate concern, though it was made easier by the fact that in the postwar period the CNCMH was to enjoy the support of Canada's social economic, professional and academic elite" (*Keeping America Sane* 170). The forging of such powerful and influential relationships would determine the course of research and treatment, as well as that of individual careers. It is not difficult at all to see the body and mind of the mad was becoming a site for all manner of personal goals for the people who studied it.

1.7 A Canadian-Focused Literature Review

Current research in Canadian mental health encompasses scholarship from the fields of community mental health, social work, social services and governmental policy documents, as well as contributions from the discipline of psychology. Research and scholarship in Canadian psychiatry includes histories of psychiatric institutions, biographical accounts of particular individuals, and reports from studies as to the efficacy of particular treatment approaches. Mental health knowledge is disseminated through individual community mental health networks and becomes standardized through mental health lexicon and best practices approaches. Psychiatric knowledge follows a similar dissemination trajectory. Both fields fork, with some knowledge becoming part of peer reviewed standardized scholarship and some knowledge being taken up by others outside of the field of expertise to describe themselves and their experiences. This thesis finds a place in this scholarship by putting what is called expert knowledge into conversation with both community and experiential knowledge as taken up by consumers, survivors,

stakeholders and care givers within the mental health system in order to balance the literature on mental health, mental illness, madness and psychiatry.

The literature review surveys some of the literature from Canadian social historians, including those critical of psychiatry, such as Thomas Szasz, who challenged the very existence of psychiatry as a science, and more explanatory historical accounts, such as have been written by Ian Dowbiggin, James Moran and David Wright, who point to more nuanced explanations for the rise of asylums and of the practice of the placement of family members in these institutions. Clifford Beers, writing in 1907 and Anne Collins provide intimate accounts of institutionalization in Montreal in the 1950s and 1960s. Beers, from his own experiences in the eastern United States and Collins, a journalist contribute the perspectives of having been treated cruelly and inhumanely while under state care. Collins' work is included in the historical analysis section of the thesis to lend credence to voices that have since been silenced by their "mad" status. The literature review surveys contemporary and archival anti-psychiatry literature, such as blogs and archived tapes and interviews from the Psychiatric Survivor Archives,Toronto.

Szasz, in his comparative study of the inquisition and the mental health movement, defines both the architecture and the purpose of the mental health movement (*The Manufacture of Madness* 281). He describes the movement in terms of its usefulness to society, just as wars have been in warring times. Detection and then insertion of increasing numbers of people into the mechanisms of the movement provides work for service providers, as Szasz sees it. He describes the state of the mental health movement in the United States as one in which "…the state and federal governments, their subdivisions, and private and philanthropic organizations are hiring more psychiatrists, psychologists, and social workers to tear more madmen out of the bowels of society" (*The Manufacture of Madness* 281) .

Ian Dowbiggin considers other reasons for the increase in institutions and the types of institutions built in exploring the link between eugenics and psychiatry at the end of the nineteenth and beginning of the twentieth centuries. Dowbiggin addresses the issue of the turn-of-the-century enthusiasm with which Canadian and American doctors took to the idea of psychiatry. This new field of medicine, a sub-field and little respected branch of psychiatry at the time, was rebranded as the answer to the widespread problems of drunkenness and madness with which the colonization project was supposedly replete. As Dowbiggin makes clear, eugenicism was touted as a "scientific" approach to this problem; it was an approach that promised, essentially, to drain out the impurity and bad blood of young Canada. Dowbiggin situates Blumer, as well as Charles Kirk Clarke, Thomas Salmon, Clarence Hincks, Helen MacMurchy and others, in an "age of 'Progressivism', stretching roughly from the 1890s to the New Deal of the 1930s" (*Keeping America Sane* Preface ix-x).

As writers of psychiatric history, such as James E. Moran, Thierry Nootens and Geoffrey Reaume, have discussed there were many trajectories to and through institutionalization. Dowbiggin focuses on the practice of immigration restriction, which was instrumental in creating a kind of noble cause out of the practice of using scientific methods such as eugenics to determine who should and who should not be allowed to contribute to the growth of the population. In Dowbiggin's description, psychiatrists (alienists) were often "cloistered….alongside patients whose behavioral traits were often erratic" (*Keeping America Sane* 8). Dowbiggin describes the transformation of psychiatry from the late nineteenth to the early twentieth century as encompassing experimentation in "psychoanalysis, eugenics, child guidance, outpatient clinics, intelligence testing, industrial psychology, and preventive mental health" (2). He also points to the almost total control that psychiatrists had over their patients,

especially when a position inside one of the many asylums was obtained. Soon though, with reports of abuses of patients, Dowbiggin describes how the "generous confidence" of psychiatry began to falter.

Dowbiggin makes clear that in advancing eugenics alienists had begun to approach the treatment of madness with the same scientific rigour with which medicine was treating other illnesses. As Dowbiggin discusses, alienists were losing their grip on their asylums for a number of reasons, not the least of which was the public outcries of abuse and growing interest in the new science of neurology (*Keeping America Sane*, 20). Dowbiggin cites this professional malaise, or the loss of "therapeutic optimism," as a "condition reflected in the sporadic recourse to desperate techniques such as lobotomies, electrotherapy, focal infection therapy, malarial shock and insulin coma treatments" (22).

Edward Shorter's work, *A History of Psychiatry*, is vast in scope and it focuses on the histories of treatments and approaches to mental illness and madness. He notes, for example, that degeneration theory was an attempt to "enlist the neurosciences in caring for patients" and that the attempt at biological psychiatry was "a movement of ideas rather than an exercise in bricks and mortar" (Shorter 69). The "whole paradigm for looking at illness changed," claims Shorter, "after 1900" (69).

As Moran and Wright suggest, medical historiography is currently being written "from below," to include the patients' perspectives and bring these narratives to the forefront (6). Moran and Wright, in *Mental Health and Canadian Society*, examine mental health history, noting that "fascination with 'madness' and the 'mad-doctor' are not limited to popular culture" (3). In a panoramic consideration of the scholarship on the topic of mental health in Canada, they make reference to the presidential address to the Royal Society of Canada, delivered in 1898, by

T. J. W. Burgess. Burgess' speech is meant to provide an overview of "the nineteenth century changes in care of the insane in all provinces and territories of Canada" (5). Moran and Wright note:

> Over one hundred years later Quentin Rae-Grant's introduction to an edited volume of articles commemorating the founding of the Canadian Psychiatric Association offers a similar prognosis of psychiatric progress as it lauds the shift from the late nineteenth century psychiatric paradigm of institutional care to the late twentieth century paradigm of community-based outpatient biological psychiatry. (5)

Citing a lack of revisionist histories of Canadian mental health scholarship, the absence of what elsewhere had been "an unprecedented scholarly attack on the traditional view of the rise of mental hospitals and the consolidation of Anglo-American psychiatry," they point to the work of Andrew Scull and David Rothman, whose views they say reject the kinder explanatory perspectives of Gerald Grob and Kathleen Jones (Moran and Wright 6).

This limitation, for Dowbiggin, is to suggest something beyond the moral agenda at play in the eugenics project of the late nineteenth and early twentieth centuries. Beers, although critical and reflective, situates himself within the psychiatric hospital system of which he eventually becomes an active part. Describing the cruel treatment he underwent at the hands of attendants of a New Haven mental hospital, Beers advocates for changes to the system but he does not challenge the existence of the system, in fact, even as he writes from within it. In American, Beers established the National Committee on Mental Hygiene, which later partnered with the Canadian Mental Health Agency. Beers' first person account of his experience in a psychiatric facility brought the treatment of people housed in institutions to light and began a period of reform of asylum practices.

Thierry Nootens focuses on individual motivations for committal. In considering other institutional changes in nineteenth century Montreal, Nootens places asylum committal squarely within the capitalist project of this period, at a time when "families were forced to make important decisions at one point or another in their history" including decisions "to emigrate, to take advantage of professional opportunities, to find satisfactory residential accommodation, to adapt to changing democratic behaviour" (49). Nootens argues that there were reasons for committal to asylums that lay beyond the initial documented diagnosis. By accessing patient records and diaries, Nootens collected enough data on admission criteria to make the claim that families in nineteenth century Montreal, striving to cope with the day-to-day realities created by an ever-changing political and economic landscape, and having no other recourse made use of the institutional system. In Nootens' account, the behaviour that initiated the admission process was often that which could bring embarrassment or financial ruin to entire generations. Nootens considers the over-arching tensions at play in the lives of Quebec families at the end of the nineteenth and the beginning of the twentieth century (49-68).

André Cellard and Marie-Claude Thifault provide historical accounts of the rise of capitalism and the place of both ethnicity and class in determining who was institutionalized. Their work reviews the earliest approaches to "caring for people with a deranged mind" and the work of a special committee "to investigate (among other things) institutions responsible" for this care. Cellard and Thifault note a distinct difference in the care of the so-called mentally deranged under a "new philosophy" that "clearly differentiated itself from that of the previous system" (97). Cellard and Thifault note this as a revolution that "witnessed the replacement of family with the state institution as the central locus of care for the mentally ill" (97). Cellard and Thifault's analyses of the rise in capitalism of the nineteenth century, and a reform movement

founded partly in concern for "potential urban disorder", as well as "enthusiastic promotion by physicians of institutional treatment" leads them to conclude that still other factors were necessary for such changes as occurred in the early asylum era of Quebec (98-99). They suggest "a new historiography of madness" that is "less concerned with socio-economic determinants" and more interested in "the mentally troubled—their identities, origins, and social and familial ties" (Cellard and Thifault 98).

In *Remembrance of Patients Past: Patient Life at the Toronto Hospital for the Insane, 1870- 1940,* Geoffrey Reaume brings to light the details of life once inside institution. By telling the stories of the inmates of 999 Toronto Hospital for the Insane, through journals and letters written by them, about them and for them, Reaume opens a window into the lives and the experiences, from admission to discharge or death, of a group of patients in this institution during the years 1870-1940 (*Remembrance).* Reaume cites the many circumstances under which one might live out one's existence in confinement at Toronto's asylum on Queen Street and addresses the issue of patients' labour and contends that inmates at the asylum at Toronto constituted an unpaid workforce disguised as a moral/therapeutic milieu (*Remembrance).*

In recent years much of the informal gathering of information and important contributions to mad knowledge and mad history have been recognized as a formal body of literature. The website "Psychiatric Survivor Archives, Toronto" co-founded by Reaume in 2001 contains artefacts, archival data and continues to collect and publish work pertinent to mad history. A colleague suggested Reaume's *Remembrance of Patients Past* and another colleague suggested I look up Don Weitz. A very short list of these prior to the important work *Mad Matters: A Critical Reader in Canadian Mad Studies,* published in 2013 includes Sally Clay, Bonnie Burstow, Kathryn Church, and Don Weitz. In *Shrink Resistant: The Struggle Against*

Psychiatry in Canada, Bonnie Burstow and Don Weitz contribute a "living testimony of psychiatrized Canadians in a unique historical collection of stories, poems, journals and graphics created by people who had the misfortune of being branded 'crazy' and imprisoned in Canadian psychiatric institutions" (19).

For historical perspectives of madness and the connection of these to present day understandings of mental illness, a search was conducted through *Academic Search Complete*. Entry of the terms, "history of psychiatry" and "Canada" yielded 36 results. More than half of these concerned pathological psychology, psychopharmacology, and nosology. Literature from this perspective assumes a particular position about madness, saying it has always existed and still exists, and about the expertise to "treat" madness, which is taken up in this thesis. One of the articles also challenges this historical perspective, bringing to bear concepts of citizenship and governmentality on the discourses of both psychiatry and citizenship in relation to mental illness (Perron, Rudge, and Holmes). About five more articles focus on mental illness and various other social or cultural categories.

"History of psychiatry" was then replaced by "mental illness" as a search term in the same database. This resulted in almost 4,000 results and so the search was narrowed to articles dealing with Ontario. This resulted in just over 2,000 results. A quick scan through these revealed that there were three main sources of publication, these being journals of psychiatry, nursing, and social work. In fact, *The Journal of Psychiatry* outweighed all other publications in this category, with over 500 results. Journals with "Mental Health" in the title showed just over 100 results. Out of this group, there still seemed to be a relative paucity of approaches that described participants of studies (where focus groups and participatory methodologies were used) as other than patients. As well, the focus of these articles, following on the heels of the

precursor to the mental health model, was on treatment outcomes and the results of particular delivery service models. The social organization within the mental health/mental illness field was described *by* professionals (such as nurses and social workers), who discussed participants as "patient," "client" or "consumer," and so therefore the perspective of these works is from an institutional or pathological lens when examining ethical and professional issues. For consistency, a search using the terms "history of mental illness" and "Canada" resulted in 39 results, many of which were also found in the first search ("history of psychiatry"). Results were more surprising when the search terms were changed to "history of mental health" and "Canada." This resulted in 50 articles. One of these, a review of the first five years of the Mental Health Commission of Canada, makes an interesting contribution to the literature on the relationships between funding bodies and public health programs, and on the place of lived experiences as valuable to knowledge (Goldbloom and Bradley). Interestingly, the first five articles in this search concern studies of people traditionally thought of as outside of the mainstream population, such as prisoners, adolescent mothers and recent immigrants.

The search term "madness and Canada" resulted in about 1,150 hits. The search was then narrowed to Ontario and over 600 results remained. About half of these did not use the concept of madness to refer to the human condition of lunacy or mental illness; mad as a word used to describe shopping, love, or ridiculousness appeared in only 24 of the titles. Madness, as it is used by mad activists, would not be likely to be found in this particular database at the present time. It is hoped that this will change and that emerging methodologies such as critical ethnography will challenge the heaviness of medicalized and professionalized perspectives of madness.

Archival sources from Sudbury and Ontario were used to bring the broader discussion of madness into conversation with local practices. For example, articles dealing with the

involvement of Dr. T. P. Dixon, a physician who was influential in the early days of organized psychiatric services, informs some of the local history. As well, other local knowledge, outside of the formal interviews, informs some of the local history. For the most part, the history of the community was obtained from historical sources such as newspapers, census data, and published histories.

E.G.Higgins, Florence Howey and Frank Peake, all local historians, make visible the social and law enforcement practices of Sudbury, encompassing almost 100 years of the community's history. For the first 60 or more years of its history, the community had no standardized method of dealing with mental illness or madness. As Higgins' history makes clear, and as Jack also recalls in his recounting of the history, people arrested for public drunkenness or any other crime against person or property were sent to the local lock up which sufficed as a jail. It was not uncommon for people suspected of madness to be sent by train to the asylums at either Mimico or Toronto.

By many accounts, it was a motley crew who arrived in the community ready to work. Using census data from the end of the nineteenth to the middle of the twentieth centuries, Donald Dennie focuses on the organization of labour in Sudbury. In 1883 workers were answering newspaper ads to come and work for the CPR as rail lines expanded across Canada. As Dennie writes:

> Thousands of navvies and labourers preparing the railway line into Sudbury from the east and from the west on the Algoma Branch swelled the numbers in Sudbury Junction. These did not all live in the boarding houses of the new community but were spread along the line from Callander to Algoma Mills, and from 1884, on the western section from Sudbury to Chapleau and Thunder Bay (Dennie 26)

Dennie describes the historical community as a company town. He writes, “the CPR attempted to control every aspect of life in the emerging community from the work of the construction crew to the sale of liquor and other necessities of life” (30). The first settlers to Sudbury outside of the labourers who worked on the rail lines were merchants from the Ottawa Valley and these people set up shops on what are now known as Elm and Durham Streets (Dennie 32).

Bringing contemporary experiences into discussion with the local and broader histories of services, as well as with present community service models, offers a unique contribution to the scholarship on experiences from within the mental health system.Primary and secondary sources were analyzed to provide some historical context for the mental health system that evolved out of the perceived needs of the emerging Sudbury community. These needs were spiritual and social and led in Sudbury to the building of many churches, a police force, medical services and eventually organized mental health services. From the rudimentary medical care given to workers on the railways described by Florence Howey to the often absurd dealings of the local police force described by E.D.Higgins, a portrait of Sudbury in its foundational days, between 1865 and 1900, emerges. I found this helpful in bringing to life the history of this most interesting northern community; the hospitals of Sudbury have their own unique history of dealing with the illness of early settlers and many of the old buildings remain.

The site of the Sudbury Algoma Sanatorium, for instance has an often told history of treating tuberculosis, mental illness and young people who were diagnosed with mental illness or disturbance. A complete social history of this community has not yet been written but stories from many perspectives are coming together. The early years provide the foundation and this thesis contributes to the rich social history of Sudbury. This is a unique community in terms of the institutional memories of local hospitals and institutions which are discussed in many of the

secondary sources. The ethnographic strand of the thesis merges with this history as participants recall specific places and times that are reflected in historical landmarks. Indeed, "The San" (Sudbury Algoma Sanatorium) remains in the narratives of local psychiatric nurses, social workers and youth workers as the place where they cut their teeth on diverse treatment modalities. I am in that number, as a child and youth worker of the 1980s and as one who came to know what it meant to look from either side of those windows. When I listen to the interview participants describe their experiences from within this building and with other pivotal pieces of the mental health system, the experiences resonate with my own local memories and with my knowledge of Ontario's broader institutional history.

A list of primary sources is included in an appendix to the works cited and includes selected reports of the inspector of prisons and asylums from 1871-1884 (Langmuir, O'Reilly), selected reports to the board of health from 1901-1903 (Bryce, Hodgetts) and a selection of addresses and an article pertaining to insanity presented and written by Burgess from 1898 to 1916. Selected articles from *The Globe, Globe and Mail* as well as local histories are held in the "Mary Shantz" collection of the Greater Sudbury Public Library.

The current mental health model has become an industry which thrives on mental health literature, research and services. Some Canadian examples of this are the Canadian Mental Health Association (CMHA) and the Canadian Alliance on Mental Illness and Mental Health, (CAMIMH) and the Centre for Addictions and Mental Health (CAMH).

Cellard and Thifault tie the rise in asylum committal in the late nineteenth century to the economic burdens faced by new immigrants. The flow of people into Canada (their focus is Lower Canada, later Quebec) included people with more or less resources, including family support for relatives considered mentally ill. This feature of mental health history represents the

flow of people into the country and into asylums. In the present exchange, people access mental health services for many reasons and do so both voluntarily and by formal process. Another key finding was to be found in the exchanges of various forms of currency within the system. The people who were interviewed accessed mental health services for many reasons; sometimes people came away from a hospital visit with a clear psychiatric diagnosis but surprisingly often there was no clear diagnosis; there were reasons beyond seeking relief for a psychiatric illness to explain involvement with the mental health system. People providing professional services described their work in many different ways as did those in the interview process who provided care and support to family members. The terms "consumer," "survivor" and "stakeholder" are relatively new ways of describing these relationships. Although these are the terms used for the purposes of the interviews, they are not without conceptual challenges, given their significance in the business world as well as the mental health system.

The terms consumer and survivor make visible changing subjectivities and expectations of those accessing services. What is expected of a consumer is not the same as that of a patient. The hybrid consumer/survivor doesn't indicate any real acknowledgment of the history of the anti-psychiatry movement, at least not in the sense that psychiatric survivor Don Weitz uses the term. Concurrently, the term stakeholder is part of strategic management lexicon. Business writer Mike Clayton situates the current use of the term to the hybridization of shareholder and stockholder, attributed to the Stanford Research Institute in the 1960s. The word gained currency, according to Clayton, "in the mid-1990's when British Prime Minister Tony Blair described the UK as a '*Stakeholder Economy'"* (Clayton).

Kathryn Church, in *Forbidden Narratives*, draws from and engages with Burstow and Weitz, and with Pat Capponi *Upstairs in the Crazy House*. Church draws from ethnographic,

sometimes autobiographical accounts and journals in much of her work. Church discusses her difficulty in situating herself. She writes:

> I was changing my life as an outgrowth of my engagement with psychiatric survivors. I could not contain these changes within my intellect or my professional life. Learning to see "consumer participation" critically caused me pain. More subtly, it caused me pain in an environment in which that pain could be neither acknowledged nor worked through. I found these circumstances intolerable. (Church 49)

Another major finding of the research involves the process of taking up the identity of a mental health consumer under the current medical, economic and political rubric. The experience of being mad has most certainly changed such that diagnoses are often accepted uncritically. This experience is embedded within a wider acceptance of the prevalence of mental illness. Interview participants discussed both what they talked about in their interviews with psychiatrists and other mental health service providers and also less formal talk among patients on hospital wards. These interviews and their connections to historical data are discussed in the next chapter.

Chapter Two: Methodology

2.1 Methods of Inquiry

The social history, organization and experiences of mental illness and the mental health system are the focus points and interrogative positions of this thesis. Critical analyses of the mental health system as it is experienced by selected people from Ontario, Canada are brought to bear on the history of the mental health system from its asylum beginnings in Ontario to the community care model. The particular ways that people engage with and experience the present mental health system opens up for critical analysis both the present and subjective experiences from within the system in the present and the appearance of madness as a social problem in the past. The critique primarily centres on two periods of mental health reform—the end of the nineteenth century and the nineteen sixties until the present. How do present day mental health consumers, survivors, stakeholders and caregivers organize and manage the access and delivery of services within Ontario's current mental health and psychiatric system? What are their actual experiences of the diagnostic and treatment processes? How does the present mental health system reflect historical ideas of madness and lunacy?

This chapter describes the methodology and methods that were used to address the questions in the thesis. Archival data were analyzed to make visible discourses around particular groups of people regarded as problematic as well as discussion around proposed institutional solutions to the management of people so identified. This approach makes visible a discourse around types of people who were said to belong in institutions of some description. My analyses center on movements of reform such as those attempted through eugenicist influences of institutionalization and immigration policies of the late nineteenth century as well as through

analysis of more recent reformations. The former, the institution and asylum era corresponds to Sudbury's as well as Ontario's early history and has been described as "stretching roughly from the 1890s to the New Deal of the 1930s, years when Americans and Canadians were inspired by the dream of reform" (Dowbiggin Preface x). Complementary analyses correspond to mental health reform and a particular period of the mental health movement in Ontario. The analysis here is toward making visible, through interviews the ways in which people socially organize within the current mental health system. The thesis bridges social historical and critical ethnographic analyses to consider other ways of being and knowing.

The historical analyses both *archaeological* and *genealogical* follow and extend Foucault's approaches, the former an archaeology of discourse and the latter a genealogy of power relations. They offer "a series of complementary historical methods" (Gutting 2). Foucault uses his theories as "temporary scaffoldings, erected for a specific purpose" (Gutting 16). In *History of Sexuality I*, Foucault's perspective changes from an analysis of histories of thought, a period where he deals with "a series of historical case studies that are mainly concerned with the emergence of a range of modern human sciences (Crowley 3) to a more focused theory aimed at "a certain form of knowledge regarding sex" (Foucault qtd. in Gutting 20).In this way, Foucault made visible certain types of power and control over how certain bodies functioned and were managed. Where Rose extends the analysis to track power through management, the focus in this thesis is on the experiences of the people upon whose bodies and minds the techniques and strategies of psychiatric power flow. The mutually constituted knowledge created through ethnographic work urge theory beyond consideration of subjective experiences of the mental health system and offer, through reflexive critical engagement other possibilities of being.

With the rise of Mad Studies, an "emerging, interdisciplinary field" other voices and perspectives of madness challenge what it means to have a mental health diagnosis or history (Gillis). In this thesis critical perspectives from within the mental health system complement the social historical analyses. Findings, primarily based on the reflexive knowledge emerging from the interviews evolve into further discussion in the final chapter of the thesis. In light of the knowledge created through the methods used, the thesis interrupts social historical and medical models of mental illness to consider the ways in which workers, relatives, people with mental illness diagnoses and mad people socially organize within the mental health system. The discussion is extended to consider wider questions of governmentality and subjectivity; what does it mean to enter the mental health system in Ontario today and what can reflexive critical ethnographies, sometimes here described as mad knowledge bring to sociological research?

The mental health movement was a gradual process, writes Szasz, coming out of the fifteenth-century witch-hunts to influence the twentieth-century hunt for the mental patient. "To be sure," writes Szasz, "once the social role of witch had been established by the irresistible combination of authoritative opinion, widespread propaganda, and popular credulity, it happened occasionally that people claimed to be witches. They declared that they experienced the ideas and feelings characteristic of witches" (*The Manufacture of Madness* Introduction xx). The ethnographic perspective informs the problem of understanding how 30 people navigate through and organize within the present and relatively recent mental health system. The perspective is also informed by my years as a frontline worker in the mental health and addiction field. I left this work in the early 2000s, at around the same time that local agencies were moving toward formal association with Local Health Integration Networks (LHINs).

My understanding of the new system of delivery of health services came about through a series of workshops meant to inform frontline workers such as myself. The delivery of services mattered to us because as counsellors, we were responsible for assessing and directing discharge plans and follow up services. It was around this time also that some of the psychiatric care beds were being moved out of North Bay into Sudbury's Kirkwood site and this sparked a great deal of controversy. The restructuring of local mental health services, further considered in Chapter Three, provides a point of more immediate analysis and a point at which those most intimately aware of and affected by such changes can enter into a critique of the present and the ways in which people experience and respond to the regulation and management of madness in new spaces of the mental health system. My initial understanding of the changes to the mental health delivery model grew into a more critical perspective over the course of twenty years. In Muskoka, I had been hired as Child and Youth Worker first at a group home and then at a large mental health facility. My position in the field of mental health was that of service provider I was immersed in the field of mental health for twenty years.

The treatment of madness in Ontario from a historical perspective culminates in a discussion of current governing practices in the mental health system in Ontario. Shifts in responsibility and control of madness, from asylums to community are traced to their present manifestations. Similar shifts can be seen in other institutions in what Peter Miller and Nikolas Rose call "families of governmentality" (17). In *Governing the Present*, they claim that "…while one could identify multiple governmentalities, one could also discern family resemblances in these ways of rendering problems thinkable at certain times and places" (Miller and Rose 17).

The figure below demonstrates the methodological process and how it came to guide the analysis of the data. A critical ethnographic lens was applied to specific Canadian texts, archival

documents and interviews, with a view toward a richer understanding of the ways in which historical relationships of power and politics laid the foundation for the current mental health system and the ways in which current and local people experience this system. The current mental health system is not the monolith it was in the asylum era; those who consume and promote its theories and products are located within and outside of a network of service delivery models and these and the people who access them are in constant flux in terms of their identity in relation to the psychiatric and mental health system. This relationship, and the social organization of the self are ongoing interrogative positions of the thesis findings.

Dowbiggin argues in *Keeping America Sane* that the ideologies associated with eugenicism played a key role in the transformation of psychiatry and Reaume in *Remembrance Patients Past* analyzed patient documents for what they described about life at what was once known as 999 Queen Street (now CAMH). Eugenicist ideologies as well as immigration policies played a key role in establishing reasons for the growth in institutions. There were many reasons, beyond diagnosis, to keep people confined. Through the very real threat of plague, mandatory vaccination policies were legitimized and in turn secured the place of medical authorities as guardians of health. When asylums began to fill up, similar persuasions were used to promote alienism or psychiatry as rational, scientific approaches to madness and to propagate ongoing debates about cure or custody.

Figure 1: A Critical Ethnographic Perspective

This thesis adds to what is known about the phenomenon of being in the contemporary mental health system by making visible the ways in which people socially organize in, around and beyond the system. Further, the thesis adds to what is known about the historical social organization of Ontario's psychiatric system by making visible the ways in which what has come to known as mental illness has historically been organized. Social historical analysis of nineteenth century Ontario asylums includes archival records, reports of inspectors of asylums, medical reports and secondary historical sources. Social historical and critical ethnographic analysis of the twentieth and twenty-first century Ontario mental health system includes a history of Ontario's mental health system, policy papers, discussion of the mental health and mental hygiene movement, the evolution of the consumer, survivor movement, researcher experience and 30 ethnographic interviews of at least one hour and between 10-20 pages each. Critical analysis of the nineteenth century asylum system focuses on practices meant to confine, restrain and punish errant bodies and on the ways in which the asylum and prison system were economically as well as socially driven. Critical analysis of the twentieth and twenty-first century focuses on practices meant to constrain and define human behavior as well as on the increasing influence of the psychiatric system on how Canadians are exposed to mental illness messages. The diagram above shows the interplay between three domains of investigation.

The history of Ontario's institution-building era, mental health reform, influential policy reports, local knowledges and histories, and transcribed first person interviews are brought into conversation and analysis through the lens of critical ethnography. The archival reports include a survey of mental health reform beginning through the careers of notable and influential people such as John Woodburn Langmuir, Dr. Peter Bryce, and Dr. Chas. Hodgetts. In terms of the broader history, documents were selected based on what they offered to the emerging discourse of madness as a social problem. Analysis and discussion is focused on the reform goals of John Langmuir, an influential reformer whose work entailed inspecting prisons and asylums. Analysis of social and public policy at the height of political discussions around immigration, health and eugenics focuses on the work of Peter Bryce and Chas. Hodgetts. Discourses hinging the social threat of lunatics to the social threat of immigrants make visible the genealogy of institutional subjects. That such subjects were objects of analysis, observation and analysis is made visible beginning with Clifford Beer's autobiographical work, and Anne Collin's much more critical analysis of the psychic driving experiments she and others were subjected to at the Allan Memorial Institute in the mid-twentieth century (*In the Sleep Room).*

The present psychiatric and mental health system is analyzed through a brief history of three of Canada's most influential research and development and mental health delivery entities. The Canadian Association of Mental Health and Mental Illness (CAMHMI), Centre for Addiction and Mental Health (CAMH) and Canadian Mental Health Association (CMHA) promote mental health literacy and work within a vast network of services to promote both mental health literacy as well as particular ways of understanding and talking about what are called mental illness and mental health.

The people interviewed stand in relation to the mental health system but do not take a stand for or against the terms used or the system itself. They contribute a rich data set of firsthand accounts of experiences in the present mental health system. The questions asked of the interview participants (Appendices 1 and 2) probe relationships and reflections from multiple perspectives and these reveal persistent gaps in how people are experiencing the mental health system and in how it presents itself for consumption. Mental health and mental illness associations today in Ontario market themselves as the only solution to an ambiguous, but troubled state of mind that is plaguing the nation and to which diagnosis and treatment is the only solution.

As stated on Ontario's Local Health Integration Networks current website, the networks (LHINs) are mandated to "plan, integrate and fund local health care" (Local Health Integration Networks). The central website is linked to each of the designated districts in Ontario and each of these uses a template to disseminate information about its funding sources, board membership and minutes, and other news items. The Centre for Addiction and Mental Health (CAMH) falls under the Toronto Central LHIN and receives some funding from the LHIN as well as "grants and funds for special programs are received from the University of Toronto, Foundations and other granting and funding bodies" (Centre for Addiction and Mental Health).

CAMH, now "Canada's largest mental health and addiction teaching hospital, as well as one of the world's leading research centres in the area of addiction and mental health" (CAMH), stands on the historic site of what was in the nineteenth century the Provincial Lunatic Asylum. The name of the institution has changed; known as "the Toronto Lunatic Asylum, the Provincial Lunatic Asylum, '999 Queen Street', and the Queen Street Mental Health Centre", the image of the gothic structure provides a fascinating contrast to the image, one click forward on the

website, of the modern Queen Street Site, the ongoing project of CAMH. In CAMH's annual report of 2014-2015, clients are identified by name as they receive counseling, and experimental treatments such as brain stimulation. The report, titled "The next BREAKTHROUGHS will happen here" documents the work of CAMH and the CAMH Foundation, the underlying body of the centre which raises awareness and funding for the work of CAMH (CAMH).

The Canadian Mental Health Association is a voluntary association whose mission is to "…facilitate[s] access to the resources people require to maintain and improve community integration, build resilience and support recovery from mental illness"(CMHA Canada).

CAMH, CAMIMH, and CMHA as organizations and associations work from different approaches to continue research into mental health causes and treatments, to reduce stigma, to increase awareness and disseminate newly emerging mental health discourse. There have been significant changes to the mental health system from its asylum foundations. Discourses and new ways of talking about mental illness, mental health and most recently mental wellness have had direct impacts on the lives of the interview participants. As well, more subtle changes in how these are discussed and expectations of wellness have implications from within the mental health system of services and these extend to expectations beyond the mental health system. All human social behavior potentially become sites of surveillance. Social and public policy changes as these have impacted perceptions of mental illness as well as access to services are considered and add to the critique of the present. The perspectives of all of the interview participants, some more influential than others in adding to the ongoing critique emerge again in the discussion of findings in Chapter Six.

Sudbury has a rich and varied past and present. A brief background of some of the most significant periods is included to provide context for the interviews. For example, mental health

services are now offered through Health Sciences North's mental health and addiction services at a number of different local sites; acute and long term care is offered on the 6th floor of the Ramsey Lake Health Centre and at the Sudbury Mental Health and Addictions- Kirkwood Place. Local people still refer to the latter as "the san" or Kirkwood and the place referred to in the interviews as "ground floor" is the first floor of the old Sudbury General Hospital, a site now being transformed into lakeside condominiums. These touchstones have meaning for the interview participants and for myself. Patients admitted to the ground floor enter a world of confusion and despair—it is often the last house on a long road of not knowing what to do. Some people enter and exit at this point again and again. Others move through the hospital system. On the ground floor, things are bad but will get better when you get moved up to the main floor. On the 5th floor you can't have shoes or clothes but on the 3rd floor everything changes when you are allowed to wear your regular clothes again. These memories, as they are described are embedded in the landscape of Sudbury.

2.2 Consumers and Survivors, Stakeholders and Caregivers

The people who agreed to be interviewed for the thesis were categorized into two groups. In the first group are people who currently access or have accessed services within the mental health system. In the second group are people who work or have worked in the delivery of services in or aligned with the mental health system as well as family members who are or have been involved with caring for people who have or have had experiences with the mental health system. The terms "consumer" and "survivor" are often expressed in the delivery of services as mutually representative. For many people, however, the semantic convenience of a forward slash erases the history and activism of psychiatrization and introduces in its place a consumer of

products, services and ideas. The uneasy conflation came about as the result of economic as well as bureaucratic decisions most visible during the Mike Harris years in Ontario.

Among funding issues that came about during the Harris government's social spending cuts of the late 1990s in Ontario was the duplication of services and gaps in services (Lurie). It was thought that the community mental health model could address these issues by collecting the identified needs of mental health consumers (even if they preferred to be called survivors) and those with addictions. In Northern Ontario this model now sees mental health and addictions services under the auspices of 14 Local Integrated Health Networks or LHINs. In terms of funding, LHINs provide the same kinds of services to the same kinds of "consumers." One may enter this system by way of a health or a mental health crisis, and may then be channeled through a series of community service programs, which ensure long-term involvement and dependence on the health care system. The main point of analysis of this paper is the subsuming of the very different and radical goals of psychiatric survivors, self-support groups and other truly independent movements under the rubric of "consumer" and all that term implies. Consuming in the community mental health model can be indicative of compliance. The consumption of medicine, of definitions, of ideologies, of therapy, of services is often perceived as "getting better" or actively participating in one's recovery.

The term "consumer" has been applied to consumers of mental health services or users of mental health services, and it came out of the collective activism of the 1960s and 1970s, as consumer advocacy as a social movement and the "needs assessment" projects arose in the 1980s. Human rights activism in the 1960s and 1970s in Canada saw black people and people of colour, lesbian, gay, transgender and bisexual people, and queer people, women and "disabled" people collectively demanding Human Rights ("Open Interview" Burstow). Around this time,

ex-patients or self-described ex-inmates of psychiatric prisons ("Notes of a Schizophrenic Shitdisturber" Weitz) began to tell their stories and to self-describe as psychiatric survivors. This was not the first time in Canadian history that people confined against their will had told their stories.

In the United States, Sally Clay, one of the first consumer advocates, writes of her first experiences doing consumer advocacy work with the Alliance for the Mentally Ill (a group of family members of consumers) and the Consumer Coalition. Clay writes of being invited to speak at the public hearing of the Office of Mental Health. Given a copy of the rights and regulations included in a document said to spell out the rights of patients confined to state hospitals, Clay was outraged to find in the document rules of behaviour for staff when faced with clients who would not comply with what was asked of them. There was, writes Clay, no mention of rights for patients ("A Personal History").

There are critical distinctions to be made in the motivations and trajectories of the first organized groups of ex-patients. They did not call themselves consumers but survivors and they refused any government funding. In the United States, these activists called themselves, among other group names, the Insane Liberation Front, Mental Patients Liberation Front, Network Against Psychiatric Assault, Project Acceptance, and Mental Patients Alliance (Clay). After years of protesting, these early activists, at least in the United States, writes Clay, eventually began to organize around offering services, rather than protesting treatment of psychiatric patients. Certainly, anti-psychiatry movements and conferences continue to critique and challenge the discourse of psychiatry, often now with a focus on pharmaceutical interventions. Historically, acts of nonviolent civil disobedience were acts of resistance against specific intrusive psychiatric treatments such as bed-strapping, confinement and electroshock treatment.

On the heels of the de-institutionalization movement, a move which relied on continued use of psychotropic medications, came a growing anti-psychiatry movement and broader public criticisms of big pharma. Corresponding growth in community mental health effectively blended the goals of publicly funded consumer oriented approaches with more radical voices. Experiential knowledge, or lived experience was valorized within specific groups and more legitimized knowledge continued to contribute more formal practices and policies, with the inclusion of lived experience from those who were willing to come out as mad. Expertism flavoured with peerism, and rationalization that pandered to new liberal ideologies of subjectivity were at the heart of the mental health movement of the Harris era.

Radical psychiatric survivors such as Don Weitz vehemently reject the offer, continuing to align only with non-government funded initiatives. Psychiatric Survivors Archives, Toronto, a grassroots organization which collects and maintains artifacts, interviews and information pertaining to psychiatric history in Canada includes, among many other perspectives those of anti-psychiatry survivors such as Weitz. .

The consumer as a political and economic entity began to take shape in the late 1980s when "the three solitudes" of psychiatric services, beds and community services were attempting to better utilize resources ("Comparative Mental Health Policy," Lurie). After decades of protesting treatment at the hands of psychiatry, ex-patients in Canada and in the United States were now demanding to be heard. The demand of ex-patients to participate in their own treatment decisions and the identified needs of the government for efficient service delivery models coincided. Talk therapies and psycho analysis entered the mainstream of television and literature and created growing interest in the psyche and relationships with self and others.

Experiences within the contemporary mental health system are read in the context of this historical background. The faces, voices and stories of the people who agreed to be interviewed move from the background to the foreground as these people offer a testimony of their own experiences. Presented below is a brief introduction of each participant. They are introduced in no particular order or hierarchy and nor are they separated by their experiences of one side or another of the mental health system. They mutually experience this system and identify in a multiplicity of forms of engagement with its ideas, policies and practices. These people were instrumental to my work on the critical ethnographic examination of mental health in contemporary Ontario, Canada.

Christopher, whose quote opens this chapter, rejects the label given to him by a psychiatrist in the 1970s. He respects this doctor. He describes with reverence this army-trained psychiatrist who threatened to physically beat the "brute' who had first threatened Christopher. I can see the appeal for Christopher in maintaining this relationship as well as Christopher's offhand dismissal of the psychiatric label in favour of something much more descriptive and useful; it's a physical ailment resulting in clumsiness and certain awkwardness with the use of his body. He colludes with the psychiatrist also in his cultural analysis of the situation. Christopher is a man out of time.

Cassie, a young woman living with a diagnosis of schizophrenia, does not face a lifetime of living within the walls of an asylum or hospital, but she does live carefully, fully aware that her behaviour and mood are being monitored by those who "run the show" (her words) and by herself. In Chapter 4, Cassie describes her experiences of being hospitalized and of coming to terms with various understandings of herself in relationship to her family and of the hospital system. Cassie's story plays a large part in the thesis. Cassie's entry into and out of the mental

health system involves some difficulties and she reflects on how, why, and in what circumstances the challenges arose for her. Her thoughtfulness about her resistance and her compliance within and outside of the mental health system allow for a closer personal approach, and it makes visible what is at stake for her as a young woman and a daughter at the many points of decisions along her life path.

Dave recalls his experiences working in the mental health system from the 1990s on. He is reflective in discussing the changes that have taken place throughout his career in counseling and mental health. In speaking with Dave, it almost seemed as if he has been taking notes throughout his career due to the high level of detail in his analysis of changing perceptions and ideologies, funding decisions and policy directions. In a way, Dave has been taking notes and these observations inform his own ideas of such complexities as autonomy, creative work, suicide and accountability. Most startling is Dave's awareness of himself within the system: he sees the ways in which "the system rearranges itself" and he notices the ways other therapists, patients and clients have responded to a shifting environment (Dave).

Pete was one of the first people I interviewed. We met through some mutual acquaintances. Pete identifies as living with a mental illness and also describes having difficulty with reading and writing. Pete had been invited by a friend to a mental health community group and had enjoyed participating in the group. He described that it was hard for him to participate because of a birth defect that makes his eyes move strangely and that outside of the mental health group he was treated like "some kind of freak." Pete's primary motivation for attending the community group was that they all had problems and so they understood what it was like to be different (Pete).

"I wasn't a little girl saying 'I want to grow up and be a drug addict and have a mental illness'… It just sort of happened that way, you know?" In these words, Holly describes her time in and out of the psychiatric system since 2006. Her journey of what she describes as psychotic and manic episodes began long before she sought relief and aid from a psychiatric hospital. For Holly, it was everybody else who was out of step. She says that she would get an idea in her head and by the next day she was "onto some other psychosis of some sort." For Holly, the psychiatric hospital has helped, even when she "had no say in (her) own treatments." Access to supports has been helpful and she considers herself a survivor of her illness, one which she says has brought her closer to God.

Sally worked as a mental health counselor from the early 1970s. Her particular focus was on rural and Aboriginal community mental health. Sally makes visible some of the cultural assumptions held by social workers during this period of time. Like Dave, Sally points to the personalization of therapeutic approaches during the 1970s. This era was described as the "me" generation, after all. Therapists and youth workers were assigned to groups or illnesses that they were particularly good at treating. In Sally's history of her work, the lens focuses on a period when personhood was at least as influential as what I will call professionalhood. In the 1970s, the organization of mental health services was very broadly situated between the long history of asylums and institutions and the move of progressively increased deinstitutionalization. Sally describes the pilot projects that came out of local hospital funding and that were comprised of travelling interdisciplinary teams. That these small, local initiatives would burgeon into the vast local health integrated networks (LHINs) and multi-sectoral service accountability agreements (M-SAAs) that have come to represent mental health services is really quite astounding. For

people, now called consumers and service providers, navigating this terrain has changed considerably.

Leo is a local artist. His relationship with mental health services is distant. He sought help years ago for what he describes as alcoholism and depression, and continues to speak with a psychiatrist and to take medication. Leo's oil and acrylic paintings depict the madness, loneliness and despair that can accompany a life of late night bar brawls and early morning remorse. Stopping drinking was the answer for Leo, he claims, "I quit drinking and that was it" (Leo). His years on the street living with depression and alcoholism have given him hard earned insights, which he conveys artistically and through his participation in this thesis.

Layla, like many of the interview participants, would be happy to disclose her identity. She is quite proud of the many contributions she has made to the community and has been active in mental health and addictions as well as other cultures in this city. Layla lived with a partner who was identified as schizophrenic. In and out of psychiatric care for years, Layla's partner died during the writing of this thesis.

Jack was an army trained psychiatrist, one of the first to practice in the city's first psychiatric facility. Jack discusses some of the practices and ways of thinking that were part of his long career. He makes visible a certain militarized way of thinking that allowed, in some cases perhaps, for the kind of social and psychotropic experimentation that was part of the cultural milieu of the 1970s. His discussion of the history of psychiatry includes the two decades before there was a psychiatric facility in Sudbury. For Jack, "the biggest challenge is making a diagnosis in the first place because the diagnosis of psychiatric illness is a matter of interpretation of people's behavior because in jail people have reasons to malinger or dissimilate and you can't automatically assume that the information being given its true or accurate" (Jack).

Jack's is one of many psychiatrists who received some of their initial training during World War Two.

Paddy is substantially younger than Jack and his training and perspective reflect a more community oriented approach to mental health. Paddy was trained in India and Ireland, and he has practiced psychiatric mental health around the world. He brings to the discussion some of the history of mental health legislation and the need, he says, to look at these from a community health model rather than from a psychiatric hospital model. Paddy suggests the need for more legislative powers to have patients comply with medication and treatment orders.

Julie is a social worker. She has worked with incarcerated prisoners and currently her job is to determine the facility to which prisoners will be sent. She discusses the many prisoners she sees who have serious mental illness diagnoses. She says that she is not sure that she would be very sane if in the same circumstances. Interestingly, Julie suggests that life might be easier for some people were they to comply with medication because at least that compliance would get them out of the psychiatric hospital.

Marcy was a teacher in the 1970s when she began to bring attention to herself for her unusual classroom practices. She describes this period and reflects that her very young students loved her unpredictable and sometimes outrageous behaviour. She also discusses the attempts of administrative staff to rein her in. When she was diagnosed with manic depression and alcoholism, Marcy began to see a psychiatrist regularly and she eventually stopped drinking. Marcy's interview was one of the longest and she sheds light on a particular period of time in which media representations of madness, through literature, biographies, films and songs, were colliding with women's actual experiences of being given psychiatric diagnoses and tranquilizing drugs, some of which were quite experimental.

Laura entered the mental health system through the recommendation of a high school teacher. Laura lives with her female partner, a woman who also acts as her advocate and care giver when she has episodes of psychosis. At the time of our interview, Laura was recovering from a long psychiatric hospitalization after having a severe episode of depression. Laura does not remember the two months in which she was hospitalized. She describes other times when her partner or the police took her to the hospital emergency department. She says that she is often talked over as if she were unable to offer any insight into her own condition. Laura was waiting for information as to when she could resume her employment. She was eager to return to work but frustrated that her illness was being treated differently than she feels it would be had she been off for other reasons, such as a pregnancy.

Quinn brings to light the experiences and realities of street life, hospital entry and exit, and poverty. It occurs to me that many of the people in these interviews have given enough insight and perspective to warrant an entire thesis based on their individual narrative alone. Quinn is one of those people. Not only does Quinn provide a vivid account of the social organization of people living on the street or who move from home to home, she also describes the place of the psychiatric hospital and the police as, at times, providing relief and, at other times, contributing to more sinister goals of surveillance and control. I have known Quinn for over twenty years and have had many informal conversations with her over the years. In much the same way that Marcy's experiences are contextualized in a particular time and place, drawing out some of the social culture of mental illness, Quinn's speech and point of view reflect a compassion and generosity that is not always visible from the outside of the mental health culture.

Jane accessed psychiatric care later in life. She came out as gay in her forties and discusses this as being part of the process of coming to terms with her identity (i.e., being gay and having a mental illness). Jane describes being surprised at her initial psychiatric assessment as the psychiatrist who saw her asked her if she was interested in getting well or is she was hoping to "get on disability" (Jane). Jane discusses the interplay of work, the Ontario Disability Support Program (ODSP), and the role of psychiatric diagnoses in facilitating entry into this system. She also describes her return to work and the unexpected reactions she received from her supervisors and coworkers.

Steven, like Cassie, experienced what he calls a drug-induced psychosis in his twenties. Steven has had frequent hospitalizations for depression and episodes of psychosis. He has had problems with chemical substances including alcohol and has attempted many courses of treatment, including psychotropic medications, shock treatments and various types of energy work. Steven is a musician and an artist. He says that he uses marijuana and alcohol to self-medicate the pain he experienced after an assault twenty years ago. Steven likes the word survivor. He has a terrific sense of the absurd and several times throughout the interview he begins to laugh and then so do I. This is an important feature of my ongoing friendship with Steven. He makes clear the limitations of language in trying to capture the ineffable absurdity of what I think Steven would also call madness and the rather mad system that tries to define it. For instance, to hear a phrase on the radio at the precise time that one of you says this phrase, or to hear something repeated three times, has significance for some mad people that many others would miss. To be able to know that this is significant, but not necessarily a terrifying indication of an imminent episode of mad meaning making, is an amusing inside joke. I have seen people react with terror to these occasions of synchronicity and I have seen people react with humour,

but it is one of those things that cannot be replicated or studied, only experienced. Although synchronicity and wordplay have long been amusing personal interests, through Steven, Cassie, Holly and others, I hear this language and the random language of the environment just a little bit differently through their ears.

Collin is a parent and official guardian to his daughter, a young woman diagnosed with schizophrenia. Collin describes the initial entry of his family into the mental health system. A phone call from his daughter's roommate indicating she was not well alerted Collin and his family, and so she was taken to the psychiatric hospital. Over the years, Collin has had to negotiate treatment orders with his now adult daughter. Collin describes changes in his relationship with his other children, his wife, his daughter, his extended family, the legal system, the hospital systems, and with the community. Collin's relationship with the past and future have also had to be renegotiated as his expectations for his daughter's life, which he admits he took for granted, have had to be changed. The interview with Collin was fittingly held in his own kitchen, in the house where his daughter had grown up and where she still often comes to stay.

Simon is very articulate and intelligent and is an exceptional writer of fiction. To be in Simon's world is to be taken up to the height of one's creativity and to have one's imagination stretched beyond the mundane, concrete reality of clocks, and of singular meaning. Simon's story includes his involvement in the mental health system in times of crisis, when he has sought relief, and regular visits to a mental health outpatient unit. Entry into the mental health system for Simon initially came about through his work place. His depression interfered with his work and he was directed to psychiatric care by his doctor. Simon entered the mental health system looking for relief. Having had first contact with the system in his early twenties, Simon now has a long history of negotiating the tensions between the temporary relief he seeks from the system

and the avoidance of intrusion in the long periods in between the episodes wherein he is unable to sleep for days. Simon hints at the problems that can result in what he describes as "unmedicated activity [resulting in]…complicated schemes to fit your hypomania" (Simon). Simon describes a complicated process of remaining out of the hospital and in charge of what medication he chooses to take. Simon's analysis of the responses to his mental illness episodes of the psychiatric hospital system and that of the larger community of family, friends, doctors, lawyers, and workplace supervisors allow for an important first-hand, long-term account of living with a mental illness and a mental illness diagnosis.

At the time of the interview, Brent spent much of his time volunteering for an alternative peer run agency. Like many community organizations, this agency has undergone quite drastic changes since Brent's time there. Brent describes a period in which he was subjected to disciplining by one of the peer managers. As Brent's story makes clear, peer run agencies, although they exist outside of the formal hospital system are not without their issues of power and intimidation. Brent challenges some of the assumptions made by clinicians in the hospital system, and, like many of the interview participants, he describes having to be careful how he conducts himself. Some of his behaviours can be read as symptomatic of mental health or of mental illness, although such a diagnosis would not necessarily be made of someone outside of a hospital setting. Brent also describes the feeling of shame he felt as a man who had been raised to believe that it was his job to support his family. Living on support payments makes even volunteering almost impossible. Since the time of the interview, Brent has had to stop driving other people to appointments and picking up food for them as he can no longer afford the gas money.

Brian was one of the first people I interviewed. Brian is another well-known person in the community. He often looks drugged and is sometimes harassed by a group of elderly men at a shopping mall. I have seen Brian walking close to his home and at arts and film events with his mother. Brian describes being taken aside while attending university and discussing with a professor what he was thinking and feeling. Brian feels that he is under surveillance by the police and he has had warnings to avoid contact with some people. Although his story is unique considering Brian's description of the earlier points in his life, which he describes as quite successful, he also represents a visible group of men of a particular age in the same community with similar trajectories into and out of the mental health system.

Mischa and Sean are social workers who discuss their individual experiences and approaches to mental health work. Mischa's approach is current and located within the psychological approaches, while Sean uses more narrative techniques, seeing mental illness as one part of a wider story. Sean has a particularly interesting way of disempowering psychiatric language to make it accessible and easy to discuss.

Tim and Rhonda were both trained as Native Social Workers. Rhonda describes some of the differences between what she calls Western practices and traditional practices. Dannie is a psychiatric nurse and she describes the changing practice of home visits. The psychiatric team often provides more hours to an in-home psychiatric patient than he or she would receive in the hospital. Dannie has been a psychiatric nurse since the opening of the first specifically psychiatric facility in the community where the interviews took place and as she nears retirement, she recounts the many changes in the mental health field over these years.

Sam is a brilliant artist who lives with his girlfriend (who is also an artist and writer). Sam discusses over coffee during our interview that he can recall a much more artistically active

period in his life. He has had to learn also to love carefully. A resistance against the siren call of creativity has been described in various ways by the more artistic and creative participants of the interviews. It is clear as Sam laments the joy he felt during highly creative periods of his life, that something has been sacrificed.

Maggie has a sister whom she loves. Maggie treats her little sister with great care and love and includes her in most of her social activities. Maggie refuses to use the word schizophrenia, instead spelling it out, "s-c-h-i-z-o-p-h-r-e-n-i-a." This word does not describe her sister. Maggie describes learning and educating herself about her sister and working her way through the mental health system to find help for her sister. Her sister now works full time and has a few friends at work.

Sophie also contributed to the thesis by sharing her experiences of providing spiritual support and guidance to the many people who come into conflict with the law, due primarily to mental health challenges. Patrick participated in an interview but was hesitant to disclose very much about his experiences as he wants no involvement with institutions of any kind. We have discussed the thesis over the years and he has disclosed his experiences which remain part of the rich background of this work.

My work in southern and northern Ontario and my memories of Glasgow institutions formed a first person perspective as well as an insider informed interpretive lens of the data. Only the person with actual experience of madness, mental illness or diagnosis of mental illness can have insider knowledge of that particular experience, but a shared knowledge of the processes, networks and systems of the mental health industry informed the research from its preliminary stages.

The interview participants discussed their own experiences of making sense of and navigating the mental health system, which has grown into a vast network of hospitals, administration, satellite agencies and community networks. LHINs and M-SAAs dictate the practice of the contemporary mental health and psychiatric industry. The actual experiences of the "consumers and survivors" and the "stakeholders" in the interviews tell a story for us about how this system is experienced and what it is like to enter and exit at different points. The choice of a particular Northern Ontario city, and the choices of particular people through which to "view" this social history are meant to make this important social history of "mad people" accessible. All of these systems and movements are inhabited and steered by human beings with sometimes colliding, sometimes colluding, and motivations. Simon experienced this aspect of the psychiatric system, saying: "I was at the admission position….it was right there…all available aid was presented but no actual help was given because I could not get either a voluntary or an involuntary position" (Simon).

The patient standing in the (sort-of) sunlight in front of the new Bell sponsored CAMH building asks us to let the shiny lighted windows in the background speak for themselves. In the 30 interviews included here, consumers and survivors and service providers and stakeholders do speak for themselves, albeit through responses to questions written by me. One of the challenges of ethnography is asking the most appropriate questions for the research goals. I asked open-ended questions to probe areas of peoples' lives that I thought might be most impacted by a diagnosis of mental illness or by the presence of what is called mental illness.

2.3 Critical Ethnography: Reflections on Madness

I have always been intrigued, fascinated and terrified by institutions so it is not surprising that my work eventually led me to work inside a few institutions. The first memory of these occurred on a sunny day in Glasgow. As a child, I was taken by my parents to visit the Thomas Fortune Work Centre, a centre designed to provide work experience for adults with learning disabilities. My brothers and sister and I played outside, while Mr. Fortune, my great-uncle, the man who had established the work centre and who had raised my Dad when his own had died, showed my parents the rest of the facilities. I had no concept of what the centre was other than the five o'clock green of the grass and the imposing red brick walls.

Years later, a second memory, or collage of memories, was formulated when I worked as a residential counselor at the Muskoka Regional Centre in Ontario. The Muskoka Centre closed in 1994. When I worked there, in the 1980s, it was a residential facility for what were then called mentally handicapped people. Many former institutional sites, including this one, have become popular attractions for urban photographers and ghost hunters. I usually worked on one floor and looked after women in a locked ward. I assisted the women with all aspects of their day to day life inside the institution, from eating and bathing to attending work and social activities. In the morning, the residents were lined up naked in preparation for showers. The image of the patients, as they were called was superimposed on the visions I had seen of prisoners of war, except that the patients did not look to be in despair as the prisoners had; some of them were smiling, fingers in mouths, others touched their genitals, and many of them yelled or screamed. Many of them were close to my age. A few of them were strikingly beautiful to my eyes and many had facial and bodily deformities. Watching them lined up against the wall, naked and vulnerable in waiting-to-pee, or waiting-to-eat stances, I recognized what was the same and what was different about me and them, a recognition which increased and deepened during my time there.

The patients were managed strictly, through routines, behaviour modification and the locks on each door and on each floor. The management of the residents was usually performed with affection and kindness. Still, the visage of institutionalization was never so apparent or profound as it was there. I often worked nightshifts alone and would come home to take a shower and found, by mid-morning, the local people or tourists who would be ordering their first drinks, Caesars as I recall, the breakfast of social drinkers, at a local resort. By October, the sound of the Bangles on the radio had died away with the hot sun and I was still staying at a boarding house and bicycling to whatever shift I was working that day. Reality had sunk in with a cold chill: I was completely lost. I found this mad world bizarre and intriguing. On my last day working at the institution, I sat on the floor during a staff meeting beside one of the more vocal patients and it occurred to me that the line between patient and staff, between regulated order and chaos had blurred completely.

My background includes several years as a child and youth and mental health counselor in the field of chemical substance abuse and concurrent disorders. I began working in this field in the 1990s when mental health reform was again in its heyday. I had been working as a primary addictions counselor from 1998 until about 2008 with women in treatment from chemical dependency. They were situated in the midst of an intricate system of overlapping services, a system that I was becoming increasingly critical of the more I knew about its policies and practices, especially its ways of increasing profits at the expense of a vulnerable group. The fault as I saw it lay not in the particular treatment centre but in a larger relationship to delivery service models and alignment with diagnosis.

This mirrors a jarring reflection of the larger, ongoing dynamic wherein the addict or mad person is always in need of punishment, correction or more recently, persuasion. Beyond the

forces or "case studies that are mainly concerned with the emergence of a range of modern human sciences" Foucault offers "…a history of societal structures (or *epistemes* in Foucault's terminology) that have produced and shaped the boundaries of knowledge, ideas, truths, representations and discursive formations in different historical periods" (Crowley 3-4).

As the interview participants discussed their relationships with their families, with the mental health system, with themselves, with their work, with the DSM and the diagnostic process, new possibilities began to take shape and push against the walls of what is known by the limiting epistemology of the mental health system. The mental health movement allows the voices of "peers" and "lived experience" and even "mad knowledge" to promote the aim of reducing stigma and to get everyone talking about mental illness. This technique seems to expand the definition of what it means to have a mental illness; after all, 1 in 5 are said to fit the diagnostic criteria ("Bell *Let's Talk*"). Implicit in the inclusion is that increasingly more people need to be directed to mental health services for treatment. However , rather than expanding the definition of mental health or reasonable behavior, the discourse actually narrows to exclude critical mad talk, other ways of describing mental illness and madness and limit experiences of despair and fear, awe and ecstasy.

The complexity that surrounds institutions, prisons and asylums in many ways contributes to the discourse created about the people who populate—some voluntarily, some by committal—these spaces. What do any of us know about the day-to-day lives of the men, women, and children in such places? What do we know about the person who walks up the stairs toward the door of the community health clinic? We know what has been written from the perspective of a particular writer who may take an interest in the subject.

Some of the people interviewed are linked to this system and to the people who come to

see them for mental health services. Their perspective provides directives for further collaborative research. Stories and narratives provide a unique point of entry into knowledge—essentially subjective positions offer the possibility from which to know through the perspective of those most affected by the context in which the interaction takes place. Through work in the intimate settings of many people in different components of the health and mental health system, I have been exposed to culturally unique sets of social organization. I am familiar with the intimacy of rubbing A-535 on the naked back of an intimate stranger. I can recall pungent rubbery smells at the mention of the word "developmental". I am aware that some of the people I see every day in wheelchairs have begun the day by negotiating a complex ritual of intimate care.

Many years ago, I had my first notable experience with ethnography, from the perspective of someone breaching the etic/emic divide. I spent one of many weekends over the course of several years volunteering at a retreat designed to help families recovering from addiction to communicate with each other. I was assigned the youth group and my task was to get them to start talking about themselves, among themselves. Amidst the glitter and glue of name tags, the kids began to talk as if I wasn't there. The divide blurred from time to time as the gallows humour of living with the chaos and unpredictability of alcoholism surfaced to rub some of the edges off of the experience. Some of the kids had had painful experiences of violence, betrayal and instability of living with parents who drank and used drugs excessively. Some of the questions were quite personal. As the young people shared their experiences, it was clear that these were being shared with great relief and gallows humour. As more of the young people identified and shared their own experiences, it was evident that the group dynamic was creating a network of trust. The youth seemed to trust that others had felt the same shame, fear, anger,

hope, disappointment and despair that they had felt in responding to the reality of living with an alcoholic parent.

Over the course of the weekend, personal family interactions and interviews were captured by a documentary film crew. The filmmaker was experienced in filming subject matter of an intimate nature: she had produced excellent documentaries about people living with mental illness and with other illnesses. It was not her ethics that disturbed me; it was the creation of a polished product, meant for some kind of consumption that missed so much of the lives of these kids, prior to and beyond the documentary.

In *Critical Ethnography*: *Method, Ethics and Performance*, Soyini Madison describes a similar experience after the public viewing of a documentary. The documentary described the horrors perpetrated against females in Ghana with specific focus on female genital mutilation. Madison had become intimately involved with the citizens of Ghana through Mahmuda Issah, who, with his organization of indigenous human rights activists, works in the same area where the woman in the documentary says she found no refuge (3). Madison, who had lived with Issah and the activists for three years and knew how tirelessly they worked, had knowledge beyond that which the documentary film portrayed. She had witnessed the situation from another angle, one that the wide lens of the camera had not quite captured, and that illuminated what she perceived to be a truer picture. The fact that the wider view had been missed disturbed her. As Madison noted, there is an entirely different reality beyond that which any one documentary can reflect.

Madison describes critical ethnography as beginning with "…an ethical responsibility to address processes of unfairness or injustice within a particular *lived* domain" (5). The researcher engaged in critical ethnography is bound, for Madison by a "…compelling sense of duty and

commitment based on moral principles of human freedom and well-being, and hence a compassion for the suffering of living beings" (5).

> In *Foucault and the Government of Disability,* Shelley Tremain writes:
>
> The hospitals, rehabilitation regimes, and training programs described in (this) book may well be your future, even if they don't seem very close to your present existence. The ways that they construct human identities, assess health and worth, and structure your daily life *will* affect you… But what if you are "normal"—sound of mind and hale of heart, standing there on your own two feet looking at this page with your naked eye, independent and sovereign over skin and meat and bone—and what if everyone important in your life is normal too? (xv)

Tremain is sounding a warning trumpet. You too, she says, may one day find yourself on the side of trouble and pain. She is at the same time suggesting that the experience is altered depending on the perspective. The thesis is situated from within the context of the mental health system of the 1980s. The first thing I noticed was talk—the ways in which phenomena were described was changing. New terms, new treatments and new programs emerged. For example, people working with clients who had what was then(late 1980s) being called chemical substance abuse disorder as well as mental health issues were being described as concurrently or co-morbidly disordered. I recall clearly being impressed by the title concurrent disorder specialist" as it was used to describe the new responsibilities of a colleague. The front lines of the industry were changing. It appeared to me as a layering up process wherein people were becoming specialists in very specific fields concurrent with new diagnostic labels and new programs. In the industrialization process we were no longer at "the front lines" of whatever war (against drugs, madness, social chaos) we were supposed to be fighting, but were at least once removed from the people on the

other side, the people we were employed to help. On the side of trouble were the troubled and troublesome people who were supposed to have less knowledge about themselves and less language with which to describe themselves. On the side of the newly formed specialists were solutions, preventive measures, programs and access to drugs and money. There was at least opportunity for abuses of power. From the inside, I began to wonder about the course of other lives traversed through the mental health system.

Painful things happen and human beings respond in various ways to illness, loss, confusion and other relational and intrapersonal events. None of us really stand outside of the experience of madness; however the "we are all mad" argument doesn't really work for me. Madness and mad talk as these have been reclaimed by some consumers and survivors work to make visible the ambiguity of the diagnostic process as well as the irrationality of some responses to and treatments of madness and mental illness. In my experience, there are people who want to talk about nothing but their anxiety, ADHD, or obsessive compulsive disorder and there are people who stand as far away as possible from any such tags. Depression remains the more silent and heavy topic, and, as is made clearer in the interviews to follow, is regarded as something contagious. In my work, I found myself often travelling the same road described by the people I interviewed, both those who had some personal experience with mental illness and those who were caregivers or professionals in the field. My affinity with the former group was more inclined toward frustration with finding useful models to describe what I felt were often pretty familiar and human experiences. As a professional, I experienced the ethical conflicts of defining increasing human experiences as in need of repair. My situation of having had direct experience and witnessing some of the contradictions in the mental health system drew me to begin to question the broader question. As Jim Thomas writes in *Doing Critical Ethnography*:

> Critical ethnography is a type of reflection that examines culture, knowledge, and action. It expands our horizons for choice and widens our experiential capacity to see, hear, and feel. It deepens and sharpens ethical commitments by forcing us to develop and act upon value commitments in the context of political agendas. Critical ethnographers describe, analyze, and open to scrutiny otherwise hidden agendas, power centres, and assumptions that inhibit, repress, and constrain. Critical scholarship requires that commonsense assumptions be questioned (Jim Thomas, 1993)

2.4 Recruitment and Analysis: Inviting Other Voices

To invite someone to participate in research is to indicate that there is something specific about that person that you wish to find out more about. Surprisingly, there was only one person invited to participate in this research who declined the invitation—he vehemently declined. Beyond being asked to speak about very personal things, each of the people invited had to accept my position as an interrogator of sorts and his or her own position as holder of experience and knowledge. There was no difficulty or even awkwardness with this process, partly because I knew or had at least met beforehand every person before the interview. Still, the invitation comes with it an acknowledgment of one person's position as researcher and of the other person's position as research participant (selected for a particular reason). Although qualitative researchers in the social sciences have worked toward blurring this dichotomy, it is impossible, due to our own participation in language and culture to completely erase it. The researcher, particularly in the case of critical ethnography, becomes aware of herself in this relationship. She may question what she thinks she knows before, during and after the interview. The aim is to probe deeper, not by changing the questions, but by reflecting on her choice of them in the first

place. This is not a free-falling leap into the unknown but an awareness that the researcher and the research participant are tethered to a similar, albeit elusive and ever-changing, social entity. Doing critical ethnographic research involves reflecting on this mutual belonging.

In this thesis, the categories used in the mental health and psychiatric system have been critically challenged and opened up for discussion of experiences of involvement in this larger system. This is a system that is moving toward invisibility and whose diagnostic power is on its way to enlivening a taken-for-grantedness hitched to claims that have been challenged both by its own professional members and by other ways of knowing and reacting to what has been called mental illness.

The impetus for the recruitment of interview participants and collection of interviews as data began with an assumption; I wondered who among the people I knew or could be introduced to had a story to tell about working or accessing mental health services in a city in northern Ontario. There were immediately about ten people in my circle of acquaintances who fit the description. A snowballing strategy was used to recruit others. As much as possible, each story or interview was regarded initially as a whole. For example, Layla, a woman I had worked with and known socially for over ten years had a story to tell about working in the field of mental health, as well as about caring for a partner who had a long history of mental illness and hospitalizations. Brian, a man I knew indirectly through casual chats at the mall over a couple of decades, might, I thought, have a story to tell based on what he told me about being shunned and called names in public. The analysis of each story began during the interview as I began to break down each person's story with interview questions. The questions were open-ended so that as much of the story-telling feature of the interview as the participant needed could be retained. Some people were true story tellers, retaining a sequence of events or an explanatory feature to

their experiences while others were more forthcoming when probing questions were asked. The next level of analysis was the use of field notes to capture my own reflections, biases, thematic, meant to reveal experiences of people living and working in the system. In the analysis process, themes emerged, and so only parts of interviews are used here, which further serves the purpose of preserving anonymity.

The participants' own ways of describing their awareness, reflections, dreams, and drawings are used to create meaningful themes. For example, Christopher describes, performances, poems, dreams, Cassie describes her use of art, as does Sam. Dave describes his own understanding of suicide; he describes this from his own working experience and reveals a process of making meaning out of the actions of others. Early on in the interview process it became clear that the relationships that people had with their mental health service providers, and with their mental health care giving work entailed a fluid negotiation of many forms of currency. Many forms of power were in transition from the moment of diagnosis through to the ongoing self-care. In this thesis, I bring forth these stories for their ability to make visible the social organization of mental illness and madness and to include the voices of those historically excluded. The people who contributed allow a particularly authentic account of the individual and personal journeys between the discrete realms of macro-madness and micro-madness, between the performances of madness as diagnosis and as identity, between being patients, consumers and survivors and with pre- and post-diagnosis ideas of self.

Thirty interviews cover a lot of ground. Each story is represented in the analysis, with some experiences being described more richly than others by the interview participants and some experiences within the system covering decades and others very brief interaction. With awareness that I was meeting people at various points in their lives, some of these easier to

experience than others, I have returned to the interviews again and again coming back each time with different, but salient points as I progressed during the same time through the historical research. The interview data is by no means exhausted at this point and I have tried to include as much as necessary from each individual story. The analysis led me to consider the role of governmentality (as described by Peter Miller and Nikolas Rose in *Governing the Present*) in the mental health system, a feature of the system that takes on more significance with increasing surveillance and self-surveillance. Of interest for ongoing analysis also is the process of becoming a mental health patient and the process of resistance, self-advocacy and subjectivity.

Within the telling of each individual story are embedded narratives that are about working, about going to the doctor, about getting help. The stories are structured around open-ended questions that often led to long descriptions of memories and reflections of past experiences; sometimes, the interview participant seems to be describing someone else's life. In Cassie's story, for example, she discusses "the girl in the green dress and boots," who is a pre-hospitalization version of herself that serves as a marker between living carelessly and living carefully. In other interviews, not all analyzed fully here, this theme comes up again: a distinction between the phases of pre-diagnosis, pre-hospitalization and post-diagnosis, and how they delineate at least two narratives of self.

The main questions this thesis is concerned with are as follows:

How do present day mental health consumers, survivors, stakeholders and caregivers organize and manage the access and delivery of services within Ontario's current mental health and psychiatric system? What are their actual experiences of the diagnostic and treatment processes? How does the present mental health system reflect historical ideas of madness and

lunacy? To address these questions, the social history and organization of madness or mental illness is the focus of this study.

Pete's story is one of wanting to belong and having just enough insider credibility to do so. Pete like many of the interview participants does not have a specific diagnosis. He was invited by a friend to go along to an alternative mental health site and had been going there, at the time of the interview for about four years. Pete said that he liked the feeling of belonging he got from the place and that he shares with the people he meets there a history of having been made fun of and called a freak. In the peer support site that he attends, he says people understand him because they have problems like him. Pete neatly categorizes people with problems from "the others", those who do not have problems and emphasizes that "the others" will call those with problems names. In school, he was called a "slow learner" which he understood as "retarded". Pete's responses have come about through his experiences of being bullied, an experience through which he learned to sort people into groups. His solution, inherent in this strategy, has been to find a group to which he does feel he belongs; he has formed an alliance within the community and feels "wanted" and that the people he has met are "going through the same stuff" that he has, namely "name calling, not being accepted and being teased". Pete's story is primarily about being socially ostracized and left out of things, especially at school. He has tried again and again to find a place to fit in.

Sally tells the story of the evolution of her career as a social worker in the late 1970s. As part of a team who assessed children through collaborative efforts between schools and social service agencies, Sally travelled to rural communities. Sally's story covers a period between the late 1970s until the 1990s and it sheds clear light on the continuously evolving field of research and treatment aimed directly at emotionally disturbed children and adolescents. Sally speaks of

her early career working with children in conflict with the law as part of the approach to dealing with youth under what was then called the Juvenile Delinquency Act. Sally's example of treating one young person makes visible both the importance given to expertise and that given to perceived individual skills.

> I can think though of an example of a case of a 16 year old that I was asked to assess. They were very concerned both at the school and with her family because she had stopped eating and… she presented as very flat affect, very… not too responsive, she was quite introverted and I was one of the people that was viewed as working well with introverted people –youth and as I did my assessment I did become concerned that this was a conscious…that not eating was a way to commit suicide as well and I had the psychiatrist have a look at her and we admitted her and she actually stayed at the san for quite a long time, for over a year before the underlying issues were revealed could be addressed she had experienced a horrific trauma in her early life and it had been completely repressed and she became depressed and there was the whole therapeutic process of trying to recover what happened so that she could process and be treated. (Sally)

Sally's description of being noted for her special skill in dealing with introverted people and youth points to a period in child and youth social service work wherein there was an overlap of professionalization and individualism. Her story also provides a long term first person account of social work beginning in the 1970s. This was the era of the troubled teen and the beginning of the daytime confessional talk show. As guests on television shows discussed repressed memory syndrome, false memory syndrome, bookstores filled with stories of autistic, disturbed children who could not be reached. One of many examples of treatment and research aimed at the

problem of disturbed children and adolescents is Thistletown Hospital, which opened in Thistletown, Ontario in 1957 and was "set up as a treatment and teaching hospital dealing with emotionally disturbed children" (Ontario Association of Child and Youth Care).Sally also discusses at length the place of stigma around mental health particularly because her team was attached to a psychiatric hospital system. Sally's story also makes visible structural differences in the delivery of services and there are important nuances in her story as she describes working from within a clinic, from wherein stigma tended to reside.

Mischa had been working in the field of mental health for about seventeen years at the time of our interview. Mischa has worked as a psychometrist and psychological associate in the hospital system. She describes the place of language in establishing a way of managing and treating clients in a hospital setting and describes also some frustration at the lack of such precision of language in an academic setting such as the place where she was working at the time of the interview. Mischa's interview makes visible the importance she gives to knowledge, emphasized through specialized language. Mischa emphasizes the complexity of hospital cases; they are often so complex that an entire team has to spend more than half a day discussing a client. The emphasis on complexity lends support for the necessity of ongoing research and increased specialization.

> I think the work is defined by the environment that you're in I think when you're in a hospital setting whether it's an inpatient or an outpatient environment the language is the same … there's the language of mental illness, right and it's easily understood because you're all speaking the same language regardless of your discipline and I think … you know now I'm in an academic setting so in an academic setting the language isn't the same and so I find that that's a tough piece for me because I don't really feel that the

> work is valued you know I'm a strong believer that if there isn't education about mental health… and mental health and mental illness are different …and if a person doesn't have mental health they can't learn because the definitions are synonymous or the goals of education are synonymous to the definition of mental health but that not really understood here and so I think a lot of education needs to happen in an educational environment to explain number one that there is a difference between mental health and mental illness and the value of both you know and recognizing the value of the work we do here and I find that that's a real hurdle for me here. In the hospital setting… I think when I was there …and I do work part time in the hospital it's just the busyness and the complexity- cases are more complex in a hospital setting people are presenting with more complex issue… in the eating disorder environment it's not uncommon to spend half a day consulting with your colleagues around the treatment of a client depending on how the client comes in terms of what symptoms and how ill they are and with an eating disorder its physical and psychological and sometimes that can get very, very complex and you have to spend more time with one client. (Mischa)

Laura describes in her interview her recent hospitalization and her upcoming return to work. Among the challenges for Laura are the assumptions about mental illness made by other people. People didn't seem to believe that she was okay, even when she told them she was. From her first illness, when she was in high school, she recalls how people reacted to her. She says, "I went back to school and the thing I found hard was people asking 'are you okay and, not just are you okay, are you *really* okay' I did end up leaving that year of school and not finishing because of that kind of thing" (Laura). At the time of the interview itself, Laura had just come home from the hospital having been there for four months, the longest stay she had ever had in the hospital.

There is a sense of Laura's awareness that she has lost something vital in those memory lapses; she can't recall for herself what happened and has to rely on her partner to fill in some of the pieces, and to assure her that she has done nothing "inappropriate". Laura is in the position of having to return to work unable to recall her last interactions with her co-workers. If she has given some subtle offense, she is left in the socially vulnerable position of not knowing, a not knowing she has no choice but to live with.

> I still don't recall that now and I still don't recall a lot of that stuff. I'll ask K did something happen at work did I do something inappropriate. Now this time for the first time in hospital for the first time I had ECT treatments too and I don't know if that's the treatment that that got me back to well what am I doing here I think it is the treatment that worked. I don't remember being at work and stuff so it's kind of scary for me to be going back to work because there's lots of things, I don't know if I did something inappropriate at work, I very well could have, I don't know though, she says I didn't but you know what I mean I'm not sure how I was behaving or what I said to people. (Laura)

2.5 Social Historical Methodology

The gathering of demographic information and the use of techniques to sort and categorize groups of people is a process through which people come to be regarded and spoken about by others—experts on the filling of asylums and the settling of countries, for example. The analyses of the written records of these processes is most closely associated with Foucault's archaeological process while the linking of the historical perspective to a critique of the present (inherent in critical ethnographic work) is most closely associated with the genealogy of both

Nietzsche and Foucault (Crowley). "Archaeology," says Úna Crowley "is a process for working through the archives of a society … and, like genealogy, is concerned with 'the history of systems of thought'; the history of societal structures (or epistemes in Foucault's terminology) that have produced and shaped the boundaries of knowledge, ideas, truths, representations and discursive formations in different historical periods" (Crowley 4).

The social historical analyses began with archival documents pertaining to the early asylums of Ontario and conclude with discussion of experiences from within the present community mental health model. Linking analyses of Ontario's early asylum era to the present community mental health model is a discussion of the evolution of the community mental health service delivery model. In Ontario, the Canadian Mental Health Association, the Canadian Alliance of Mental Illness and Mental Health and the Centre for Addiction and Mental Health are the primary resources for fund raising, research and knowledge dissemination for mental health services in Ontario. As mad people and people diagnosed with mental illness began to be released from institutions, outpatient services and community mental health services, often attached to teaching and research hospitals, were offered as a more inclusive model. The system itself has been challenged by psychiatric survivors who claim to have been psychiatrically abused by drugs, shock treatment and lobotomies.

Psychiatric survivors have yet to experience public acknowledgment or accountability for these abuses, nor attempts at truth and reconciliation familiar to other Canadians who have experienced systemic abuses at the hands of government funded institutions. Indeed, when they do speak out, mad people are more likely to be ridiculed or dismissed. Commenting on the rise of mad studies as an emerging new discipline, Professor Don Addington says such critiques offer "nothing new" and objects to the critiques on psychiatry and the blame it receives for "150 years

of incarcerations" (qtd. in Gillis). Addington cleverly frames his defense by linking critiques against psychiatry with Scientology and the critique from this organization, says the articles author, Alex Gillis (*The Rise of Mad Studies).* Where psychiatry was once thought of as an impenetrable monolith, it is becoming less concrete, even as the shadow side of its gaze is brought into the foreground for critical analysis. The voices of the mad, those who identify without invitation, those who identify as survivors or consumers and those who, like Simon, know their psychiatric history and sardonically self-describe as mental defectives are in unique positions to describe the new mental health system.

History can be made to speak also. The Muskoka Center now sits, like many abandoned institutions, as an empty shell. It is rumoured to have been used for canine training and is a well-known hotspot for urban exploration. In my memory, I am standing outside with the patients who are going to work. A psychiatrist with one of those fitting names, perhaps Dr. Pierce, calls out to a fifty-year-old woman—Clara—who is holding a doll. For some unnamed behavior, Dr. Pierce calls out to Clara that it is in the works; he is threatening to send her to Smith Falls. I don't know at this time what Smith Falls is, but I know from his tone that it is not good. Behind her out-of-date horn-rimmed glasses, Clara's eyes look frightened. She tightly clutches her doll and begins to cry. What power ("It was right there…all available aid was presented but no actual help was given" [Simon]).

2.6 Interdisciplinary Theory and Method

Just as the interview data is read through a critical ethnographic lens, with the understanding that insiders in the mental health system make visible social relations not otherwise immediately apparent, so are the historical documents read. It seemed obvious to me

from the beginning of the thesis that in order to understand madness, I would have to talk to mad people and that the concept of madness it would have to be traced to the places and spaces where it was formally acknowledged. Of equal methodological concern was the question of coming to know about people's experiences from within the contemporary mental health system. A quickly emerging theme was the notion of seeing oneself in this system, a process that began with selection for the interviews. Concurrently, historical methods, the analysis of particular periods in Ontario's mad history are intertwined with sociological methods; the documents render visible complex social relations of political, economic, discursive and personal power tethered to a history of more traditional and visible forms of power. To bring these relations into discussion required an interdisciplinary process of bringing the past into conversation with the present, a conversation that is begun in this thesis. Accomplished through this methodology is a clearer understanding of the historical and contemporary modes of service delivery and intimate experiences of these.

As addressed earlier, the latest fifth edition of the DSM (the DSM-V) and the privileged position of the psychiatrist are being challenged by an emerging discourse that rejects the labeling system as no more able to address the spectacular range of human experience than does a rigid binary gender system. The caveat is that this slowly evolving paradigm is at times at risk of reifying the same system through the continued marginalization, or worse, polite condescension of "lived experience," "peer" categories and "bottom up" research. Those in the most powerful research and academic positions do not refer to each other as peers, but as colleagues, for example. The *Let's Talk* campaign may indeed provide many research opportunities for ambitious academics of many experiences but the institutional workplace for many is becoming ever more tightly regulated under the banner of safety and risk management.

The analytic ground has shifted such that it is necessary to examine such paradoxes; in a critical ethnography that has sometimes (of necessity) blurred into critical autoethnography, the focus on the researcher has at times been sharp, and I am equally sure there are blind spots also. As James A. Holstein and Jaber F. Gubrium argues, "The pendulum has even doubled back on itself as postmodern sensibilities refocus the analytic project on itself, viewing it as a source of social reality in its own right" (qtd. in Denzin and Lincoln, 483).

Beyond the whys and wherefores of such ethnomethodological concerns about local social action, Foucault suggests a step back into historical and cultural beginnings. This turn toward broader discourses has enacted and put into action the possibility of bringing the history of psychiatric and mental health technologies into conversation with local practices of both the technology of "relief" (e.g., getting an admission to the hospital) with the personal, private forms of "resistance" (*Technologies of the Self*).

Those who use the services of the mental health and psychiatric system actively participate in the medicalization process, even when at their most vulnerable, at the point of needing a voluntary admission, for example. "Even the weak," write Holstein and Gubrium, "'powerfully' participate in the discourse that defines them as weak" (qtd. in Denzin and Lincoln 491). But the patient, consumer, survivor and caregiver are not without agency, even against the background of such power once they see it. Foucault's archaeological project in *Birth of the Clinic* takes us back to the point, particularly in recognizing that language before the metanarrative of madness could exist. He asserts right from the beginning that the book is about seeing, about the cultivation of the medical gaze (Introduction x). The medicalization of Western society relies on such a gaze, based on empirical observation and on the status of the observer. Foucault describes the formation of this gaze:

> At the beginning of the nineteenth century, doctors described what for centuries had remained below the threshold of the visible and the expressible, but this did not mean that, after years of over-indulging in speculation, they had begun to perceive once again, or that they listened to reason rather than imagination; it meant that the relation between the visible and the invisible-which is necessary to all concrete knowledge-changed its structure, revealing through gaze and language what had previously been below and beyond their domain. A new alliance was forged between words and things enabling one to *see* and to *say*. (*Birth* Introduction xiii)

2.7 Ethics

This study was fully reviewed and approved by the Research Ethics Board at Laurentian University.However, there are still many ethical openings that are of interest to discuss. This section outlines some of these openings and describes the ethical processes and dilemmas inherent in the work. Some of the research participants know me through my former work with them, through placements, and through mutual friends and acquaintances. Our life stories have been enmeshed intertwined, divergent, caught up again in the rhythms and beats of a smallish community of even smaller cultures. Art gallery showings, farmers' markets, public libraries, independent coffee shops and bistros, festivals of all descriptions—the mad and the artistic have both always liked like these places. There are more of such places in the community than there used to be, and I regularly run into the people who participated as consumer/survivors in the ethnography. One or two ask how the thesis is going, and one or two want to attend the defense. Most have never mentioned it again. Perhaps our conversation, in their living room, or my living room, on the beach, or at the library was just one of many conversations we had. I wanted to study and work in this community as it is particularly interesting to me for its diverse population.

As well, the community seemed just big enough to have most of the same mental health services one might find in a larger city, but small enough that I wondered about the relationship people had with those services. That I knew a few of the people through work and community and had been introduced to others through increasingly wider concentric circles of acquaintances lent a sense of intimacy to the interviews that is a feature of ethnographic work. This worked both for and against critical analysis of the interviews. On the one hand, my closeness to some of the people in both categories had allowed me entry into the subcultures of consumers of services, those who actively resisted services and made the system work for them. I was also brought into discussions of frustrations of people working within the system. Some of these insights and relationships had been the original impetus as I had over the years breached the formal boundaries of both sides of the mental health system. That psychiatric power flowed in and through all of the spaces became another focus of reflexive knowledge production and here, having a common language and a certain informal knowingness was helpful in working through these analyses. In addition, the community simply has an interesting history, which is discussed in Chapter Four. As well, in many cases, even with people I had recently been introduced to, there was a blurring of epistemological authority necessary for mutually created knowledge.

Present-day mental health language is a politicized language. There is a healthy way to be mentally ill. This apparent softening of language happens in the foreground of an established and powerful authority, which can get under the skin and under the skull. Alongside discussions of rights issues, which often only end up in relationships of tolerance, legalized and institutionalized social obedience, and access to the conveyor belt of services for the mad or mentally ill, it is illuminating to break apart and rupture the power of medicine at its core, which is the strategic use of language or rhetoric. For example, one can be either doing well, in the

regulating language of the mental health movement, or not doing well at all.

Although psychiatric survivors and bloggers tend to have much more descriptive (using words like sadness and rage) and much less Likert-scale types of responses, the power of language to influence one's experience of self is such that many bloggers use trigger warnings when discussing experiences. What is important to note here is not that mental health services are unhelpful, as at times psychiatric facilities and mental health services can offer great relief (as will be discussed further in the analysis of narratives) but that this is not always the case for all. Patients, when they become "patients," enter into a bargain of power loss that does necessarily extend to psychiatry's branches in the community, into the former's professionalization, medicalization and expertization, and in the very trajectory of here to there implications. Indeed, because psychiatry has been steeped in mystery/power, the possessor of the cultural and material artifacts of that mystery/power, to a greater or lesser degree, can ascribe as well as prescribe.

2.8 The Interview Process

In each interview, I introduced myself and explained my role as researcher. I understood that I was also a friend, coworker, colleague or acquaintance to almost all of the people who participated. In most cases, the participant read the letter of consent, or, in one or two cases, I was asked to read the letter for the participant. All participants read and signed the letter of consent, giving me permission to tape record the interview. I used the first letter of the participants' name to introduce the interview on the recording to protect identities. Once the interviews were transcribed, which was itself part of the analytical process, the participants were assigned pseudonyms and the tapes were erased.

The interviews took place wherever the participant suggested and these locations included participants' homes, my home, the library, a couple of coffee shops that were large enough to have private areas, participants' workplaces and offices, and parks. It is interesting even to reflect on the various locations. The face-to-face, semi-structured, narrative interviews took place over a period of approximately twelve months. Field notes were written up after the interviews and these were sometimes used for further reflection. Scheduling of interview sessions was arranged as per a mutually agreeable time. The participants were invited to choose a pseudonym, and a few of them chose their own names. In all other interviews, I chose names randomly and all identifying information was removed from the transcripts.

Potential risks were identified as the discomfort of discussing difficult or painful emotions. The participants in the service provider/caregiver group were at least as likely to express difficulty discussing painful events associated with their work or their obligation to family members. I have been in contact with most of the people who participated and no one has expressed any issues associated with participation in this ethnographic study.

Beginning with a few friends and acquaintances, some of whom had received services through the mental health system, a snowballing technique quite easily found the required 30 people who participated in the interviews. The 30 people comprised two groups, these being a consumer/survivor group and the other being a service provider/stakeholder. No one objected to or questioned the use of the term survivor, which is in essence a term of resistance against psychiatry. Many of the participants in this group described the term as connoting an emergence, as if coming out from a battle or difficult situation. To meet the criteria for mental health survivors, the participants needed only to self-identify as having had some involvement or diagnosis of mental illness. I did not want to dissuade people who had rejected or resisted

diagnosis or treatment, so the self-identification process was open ended in terms of level of involvement in the mental health system. As it turned out, this criterion was not in any way limiting as the participants who self-identified as mental health survivors discussed participation in various treatments and long periods of time of non-involvement. One participant, Christopher, spoke of being labeled with a diagnosis that he completely rejected, and yet, he continued to see the diagnosing psychiatrist because it was helpful to have someone who understood him. One of the precluding factors for involvement was a state of crisis or hospitalization. While one participant was waiting for a bed, she felt that the process of participating in the interview would be helpful rather than harmful. The participants in the service provider/caregiver group were comprised of people with whom I had worked and other contacts who had family members who had been diagnosed with mental illness. This group was be comprised of family members, frontline workers, nurses, mental health and addiction workers, concurrent disorder specialists, and clergy members who had been or were presently involved in the treatment of mental health issues.

To understand the social organization of madness or mental illness is to acknowledge that those who self-identify as mad or mentally ill exist and make sense of their lives outside of these institutions (although this shared history is often a component of social organization). Most lives are lived outside of the institution even if what the psychiatric institution represents has a powerful influence on how people make sense of their lives, when they are “ill,” and when they are “well.” This power to diagnose, and to prognosticate, is supported by research and medical organizations. It is this sense of the power to “make well” and “offer relief” that makes the institution both seductive and repulsive. It offers an enclave in a culture hostile toward difference. It is a fast stop when the ride has become too precarious and it becomes a prison

when madness is a siren call. As a culture, madness and its organizational events can be understood within the framework of "a movement away from the universalistic ambitions of master-narratives…a dissolution of symbolic hierarchies…the aestheticization of everyday life…a decentring of the subject, whose sense of identity and biographical continuity give way to fragmentation and superficial play with images, sensations and "multi-phrenic intensities." (Featherstone 48). The decentering of the subject and the multiphrenic postmodern identities connote a kind of blurring of media saturated identities and, among this media of course, the ever increasing public service announcement must be counted.

Studies of society and culture have also undergone transformations, such that perspectives of each are being challenged as perpetuating perceptions of vulnerability and inability. As an organizing member of Disabled People Against Cuts (DPAC), an organization coming out of mass protests against austerity measures in Birmingham, England writes, "inappropriate and misleading labels such as 'the disabled' or 'vulnerable adults and children' reinforce prejudice and discrimination" (DPAC).

2.9 Emerging Themes

Gradually through listening to the interviews and reading the transcripts, themes began to emerge. What became clearer and clearer was that patients, survivors, counselors, sisters, fathers, psychologists, social workers, and nurses had a much to say beyond what was discussed professionally. As a rule only a few people were concerned with terminology but many could discuss the ways in which terms were used. Language was far more descriptive and personal when people were talking about their own experiences of madness or when people were describing witnessing a relative or loved one go through the process of madness. Those in the

consumer/survivor group spoke of holding back thoughts of repressing aspects of themselves because they would be shunned by others. Tension between repression and relief emerged as people spoke about the relief of sleep or sedation after a period of being high, or manic. People who had been hospitalized learned to live carefully, even prescriptively to avoid further hospitalizations.

Many people who had experienced madness lamented earlier experiences in their lives, when they were more creative during a manic episode. This was a double edged sword for some who admitted to a danger in those heightened states. Professional service providers made visible their own negotiations and tensions between their own ideas about madness and mental illness and those of the mental health system. Many of them had witnessed the increasing medicalization of the mental health system, and they too lamented for a time past when greater autonomy and collegiality grounded their work. There were certainly issues specific to gender and race that could be opened up in ongoing analysis of this rich data set. Each theme could provide an analytical focus for many of the interviews. For example, almost all of the interviews, from both groups, could be read through the lens of "Living Carefully". This would have provided an interesting sociological analysis of the experiences of some people living and working in the mental health system in Ontario. However, that each theme emerged out of the data, multiple themes lent themselves to the goal of hearing and listening to the stories as stand-alone, but thematically inter-connected experiences. Following are a few quotes from the interview data and a description of the initial themes.

"I heard voices. I would act on the voices because I believed the voices. That was my reality. So if a voice told me to do something I would do it. One was to kill my ex, for example,

or, I had a huge fear , like agoraphobic that I was going to jump off a bridge and take my own life, like out of control. Even when I didn't want to. Even when I didn't want to" (Holly).

"To put it nicely they'd say 'your kid is retarded' " (Pete).

"The treatment was long and hard and I'm talking hospital stays. Hospital stays and forms that I had partial disagreement to but abided by and eventually broke free from" (Cassie).

"Well the only, it [diagnosis of clinical depression] didn't really mean anything to me except that it meant that, okay, if I let anyone know about this I will be treated as shitty as I was before when I was on the street. For many years I was treated really badly, was called fucking asshole, fucking lowlife by police for example and business owners. You know you start out like a child being called stupid and over time, you start to think you are stupid so it doesn't do any good for your self-esteem to be called the same old lines for years" (Leo).

"Well, for a person with a mental illness anything with the SKZ in it is offensive, anything like schizophrenia or schizoaffective" (Simon).

"There's nothing in that book, the DSM, that speaks to treatment, nothing whatsoever, nonetheless, the things that are described there became accepted in the broader culture, as real things" (Sean).

"I wasn't really interested in the mental health system. It's called mental health system, it's really focused on mental illness but when I first started [1990], it was really, it was a time when there was a lot of freedom to do things and there was, I wouldn't necessarily say a therapy culture but it was certainly not as rigid or medicalized as it has become" (Dave).

"She wants to come down. Coming down, there's an arc, I call it an arc. They're in a manic state or schizophrenic or whatever you want to call it, and it's okay, they feel really good but there's an arc right here, right about here before they crash, when they want to medicate so that they can come down and sleep because they're so tired, it's exhausting" (Layla).

"Like, you can actually see what's going on. You can actually, you want to get away, go in your bedroom, shut the door, not communicate, maybe you're getting yelled at because, and shaking, physically shaking from anxiety, loathing, like all of it happens and it's all negative and that's why there's such a high suicide rate" (Layla).

One of the most poignant themes was that of having to live carefully. About five of the people in the consumer/survivor group spoke of the seductive call of the other, blissful side of madness. Simon spoke of this, and of the pain that came at the end of such an experience. The need for relief, whether that was in the form of sedation or rest, or guidance and structure, worked in tension with having to repress parts of the self. Living carefully was closely tied to this tension of repression and relief. Cassie spoke of this as her stand-outness, and she lamented that there were parts of her that she was sure people missed. Living carefully did emerge as a separate theme, one for which almost all of the participants alluded to and one which was separate from any formal system such as the hospital.

Another theme that became visible was that of repression and relief and the process of getting in and getting out of the hospital system. This often involved hiding and revealing certain aspects of self. In the consumer/survivor group, the focus was on the negotiation of or navigation through various relationships within the family, at work, within the hospital system and in the broader community. These have been conceptualized as relationships that involve negotiation and navigation. Most of the people interviewed were familiar with the hospital system, and they

spoke of the intake process with familiarity. They knew what it took to get an admission. There was also negotiation, though, of what was expected to be able to be released from the hospital, and a negotiation of what the diagnosis signified to the person receiving it and to the others who might become aware of the diagnosis. All of these relationships had to be worked out and organized in terms of what would be shared with coworkers, professionals and family members, and in terms of how much involvement others would have.

People accessed help for many reasons. Sometimes all that was needed was a few days of sleep, and sometimes people needed medical support to take time off work or return to work. The theme of getting in runs through many of the interviews with both the stakeholders and caregivers as well as those seeking mental health services for themselves. Once inside the hospital, the struggle begins to either be released or to stay longer. Behaviour of psychiatric patients is scrutinized in the hospital setting and sometimes people feel that they are misunderstood or read differently because of the hospital setting.

Making meaning out of diagnosis is a process that for many involved seeing oneself through different periods of time. Some people described trying to make meaning or sense out of a diagnosis of mental illness in the context of their past and future. There was a sense of nostalgia implicit in some of the interviews as people reflected on a time before they had a diagnosis, or with the first entry into the mental health system or hospital. In making meaning out of the whole story, Cassie expresses that she was aware that there were issues before she was diagnosed such that it made more sense when she did have a diagnosis. Others, though, such as Simon, had to make sense out of their experiences from outside the realm of the hospital. For Simon, the sense of his experience is found in other temporal and spatial realities and the hospital's only real purpose in his most significant event was to sedate him so that his body

could recover from his experience. People also made sense of their insights through specialized language, codes, and synchronistic appearances of letters, numbers and words. For some people, such as Quinn, there were responsibilities that had to be understood and negotiated, such as protecting people on the street and hearing the confession of abuses in the hospital system.

In the service provider/stakeholder group discussions about mental health crises, suicide, the encounter movement and the power of language is described in the theme of cures, treatments and waiting rooms. Dave in particular made visible and personal the long history of social work and the place of creativity in doing this work. Dave also made clear the place of autonomy for the client and for the worker. About five of the participants in this group spoke of being aware of unfavourable or cruel perceptions of others and of having to advocate for their client or family member. The theme of the institutional gaze emerged also in most of the participants in this group. A father spoke of the hospital system as being tied up in other social services such that patients and clients were always on a conveyor belt of services.

As Tim's story reveals, there were other ways of seeing and saying, just as there were other ways of organizing and managing madness before the institutional building period of the eighteenth and nineteenth centuries. Certainly it is acknowledged that once the institutions were built, they rapidly filled, suggesting that, for many, the first institutions represented a solution. We might also consider that decisions about what to do with a mad family member were made in the context of an established medicalization of madness and in the midst of increasing industrialization and urbanization of northern Ontario. As more families moved into cities and as families became fragmented, people became subject to a wider medicalized and socially regulated gaze.

Tim's traditional ways of healing include ceremony, talk, and a philosophy of restoration

to balance and recognition of a hierarchical relationship. Tim is recognized as a healer and, by his account, as holder of a pipe, he must maintain his own balance. He is no more or less inclined to imbalance, but has been entrusted to restore balance to those who seek him out. Tim's healing practice is not separated from the everyday, but part of it. It is the everyday that causes the imbalance and so it is in the everyday that healing and restoration of internal and external balance must occur. Tim does suggest in his healing ceremonies a type of regulation of these imbalances, a self-regulation that comes with maturity and with respect for one's identity as a man or as a woman. In more contemporary practices, acknowledgment of the fluidity of gender is incorporated in the awareness of two-spirit people; Tim meets people where they are, without much regard or attention to some of the technologies of mental health practice. He claims to have healed people of physical illnesses and of mental and emotional imbalances by invoking powerful forces in the traditional sweat lodge. Tim is a member of the Bear Clan. We have met often before his participation in this interview and afterwards. Tim would put his hand on my shoulder and share with me his traditional teachings. Our meetings are seldom planned but often occur in the unlikeliest of places and the most fortunate of circumstances. I have shared my knowledge of Tim at length because it is not something that has ever seemed hurried. His and other service providers' perspectives enrich the research, in explaining how they resist and adapt or, in Tim's case, work outside of the medicalized model entirely.

The stories of caregivers and of those accessing services help to address specific moments and contradictions within the mental health industry. We will read how people came to be seen as mentally ill and how they came to see themselves as such. We will read about people performing their patienthood in order to get something from the system and about how people organize, negotiate, strategize and make the mental health system work for them in ways other

than incarceration. The historical foundation of the mental health industry is brought into focus by those who navigate it. Through critical analysis of these stories, we see the historical underpinnings of psychiatry (and the helping profession in general) as well as new ways of understanding the diagnostic and treatment process and the new ways of being a mental health consumer. Finally, after the analyses of each of these stories, the conclusion will revisit the history in light of the present day in a discussion of the contemporary mental health and psychiatric system. The encroachment of the medical gaze into ever increasing areas of human lives, through media and technology, and the implications of such a vast sweep for the everyday (as well as the darkest days of human existence) will round out the thesis and suggest future directions. I have tried not to solidify concepts of power or agency as I see these as working through and with individuals and systems. Of the more influential corpora of literature to emerge since the 1980s are mental health literature and mad blogs. The former asserts its power and voice through peer reviewed mental health literature, which is the traditional method of asserting dominance in the medical field. The latter, mad blogs, seems to be increasing in the organization and outlining of collective action lawsuits aimed at psychiatric treatment, sharing of documentaries exposing the use and abuse of behavioural therapies used in group homes and adolescent treatment centres, as well as creating a space for sharing experiences of madness within and outside of formalized systems.

2.10 Summary

The questions this thesis is concerned with are: How do present day mental health consumers, survivors, stakeholders and caregivers organize and manage the access and delivery of services within Ontario's current mental health and psychiatric system? What are their actual

experiences of the diagnostic and treatment processes? How does the present mental health system reflect historical ideas of madness and lunacy? To address these questions, the social history and organization of madness or mental illness is the focus of this study. The interviews were conducted concurrently with historical research. The products of the research—contemporary data, historical data and interview data, were considered in the last analyses for what they made clearer about the social organization of the foundational and historical tributaries as well the contemporary configurations and manifestations of psychiatry and its discourses. Well informed local and contemporary experts—those who experience the effects of this system firsthand and those who use its language and policies to understand, manage and regulate their clients—provide a multi-level, multi-perspective interrogation of the mental health system for further analyses.

Making history speak is a daunting task of making the past speak. Many of the urban explorers who hike up to Muskoka Centre perhaps experience it as a fascinating piece of urban history. Perhaps some of them also recall, as I do, a memory from a long time ago. Places like this, and Ontario has many, are where romantic fascination with mad hatters and mad lovers come crashing into the concrete sterility of green walls and rusting padlocks. What had Clara done to find herself here? In my time with her, the worst I ever saw was that she sounded and behaved like a very young child. There were others who bit, hit, lit fires, liked sex, screamed, couldn't talk and couldn't see. In other institutions, people were locked up for other reasons, with other treatments. Making the history of psychiatry speak involves a careful analysis of the purposes of asylums, the people who were in asylums and the making real and audible the voices of those inside the walls of the asylums. The voices of mad people in the present collectively and personally interrogate the psychiatric history of Ontario.

The next chapter provides a social history of madness. Online historical sources as well as tangible written records illuminated a life of big ideas and personal goals, many of which saw life in new asylums and new policies for the treatment of those considered dangerous to be at large, dangerous to procreate, and dangerous to Ontario's new ideas of itself.

Chapter Three: Social Historical Analysis

3.1 Introduction

> Never console yourself into believing that the terror has passed, for it looms as large and evil today as it did in the despicable era of Bedlam. (Frances Farmer, attributed quote)

In 1848 in Ontario it was considered a social coup to receive an invitation to the Annual Lunatic Asylum Ball. One attendee was so elated with the event that he or she wanted to share the experience with readers of the *The Globe*. On February 23, 1848, the person described in a letter the events of the night before:

> About 9 o'clock, the lunatics withdrew to partake of some refreshments, and the visitors having got over the feeling of sadness, which naturally pervades the mind in contemplating such a number of shattered intellects, enjoyed themselves in a set of quadrilles. Wishing to see as much as possible of the insane, we accompanied them downstairs, and watched their movements with tolerable closeness. (Spectator 62).

That asylums and the people in them were the stuff of curiosity can be attributed to such sensationalism as well as other stories which sometimes made it into the press. As the early asylums were organized, men were selected and appointed to supervise them in various

capacities and sometimes to deal with “the acute political embarrassment to the government” that some of the asylums had quickly become (Brown).

T.J.W. Burgess worked for a time at the Asylum for the Insane in Toronto, joining the medical staff there directly after his graduation from the University of Toronto at (Grenier). The full name is Thomas Joseph Workman Burgess, a name handed down to him by his Godfather, Joseph Workman (Grenier). The elder Workman, like so many others instrumental in the pre-confederation social reform movement, saw his career take “an abrupt turn” with his 1853 appointment as medical superintendent of the Provincial Lunatic Asylum in Toronto (Brown). Workman’s biographer, Thomas E. Brown describes the tasks of Workman, which followed on the “principles of ‘moral treatment’…then being introduced in England, France, and the United States” (Brown). The notorious 999 Queen Street was the building in question and this was to be an asylum to accommodate all those for whom, prior to 1830, “no legislative provision had been made”, including “ ‘quiet lunatics,’ who posed no threat to the community [and] were either boarded out to another family or ‘warned out’ of the community entirely’”(Brown). From the beginning of the asylum solution, gruesome rumours made their way to the local press, with charges that “the lunatic asylum [had been turned into] a Dissecting Room” for the services of medical students (Brown). Such was the state of affairs when Joseph Workman took charge in 1853, turning it, with the aid of an *Act for the Better Management of the Provincial Lunatic Asylum at Toronto*, into “a model institution” within a year (Brown).

The rumours of dissection, of which the inmates and patients were the victims and not the perpetrators surely cast an ugly and gruesome specter on this first asylum, a stigma which patients would wear for at least another decade. Workman’s namesake, Thomas Joseph Workman Burgess worked briefly at the Asylum for the Insane in Toronto as it was then called

and was posted "as assistant physician and then as assistant superintendent" at the Asylum for the Insane in London from 1875 to 1887, whereupon he moved to first to the asylum in Hamilton and then to the Protestant Hospital for the Insane in Verdun, Quebec; he remained there as superintendent for the rest of his career (Grenier).

Burgess and Workman published quite prolifically, the former being as interested in botany as he was in insanity and the latter publishing extensively in the areas of insanity as well as on the contagious nature of cholera (Grenier; Brown). Burgess contributed to what is known about asylum history with a presentation to the Royal Society of Canada, in 1898 (*Historical*). In this address, Burgess describes detailed, province by province accounts of the state of affairs in terms of asylums, addressing the urgent need of these as stated by his colleagues as far back as 1840 at which time, in Toronto at least "accommodation for the insane was urgent" (*Historical* 19). Throughout Burgess' address the mad are variously described as afflicted, unfortunate and as lunatics (*Historical* 19-20). Burgess also describes the foundation of the first asylum, a re-purposed York jail "situated between Toronto and Church streets" where "in its basement cells there had been confined a number of lunatics" (*Historical* 20). Describing the good work of his colleague the Hon. Robert S. Jamieson in moving the lunatics from the basement to the debtors quarters, Burgess emphasizes the "happy change wrought thereby in the condition of the wretched prison lunatics"(*Historical* 20). Burgess cites Jamieson's 1841 report to the Lieutenant-Governor:

> The patients (heretofore confined as prisoners) were taken from the cells in which they were closely confined, and from which they had long, from the dire necessity of the case, been permitted to remain in filth and nakedness and impure air, all confirming their maladies, and placed in the now purified and airy debtors' room, carefully washed,

> clothed and placed under medical care, their food critically adapted to their physical state (Jamieson, qtd. in Burgess *Historical* 20).

Within a few paragraphs, former lunatic prisoners are transformed into patients as the first asylum is literally built around Ontario's first seventeen formally institutionalized lunatics (*Historical* 20). A patina of care eventually covered the image of the grimy walls to which they had been chained. What emerged was a re-branding of what institutional care could accommodate, with the separation of the prisoner and the lunatic was the birth of the lunatic asylum in Ontario. As an extension of what were promoted as more compassionate, less punitive approaches to lunatics, because of their status as unfortunate and ill rather than incorrigible and bad, the machinery of research and management geared up for the next separation—that of the curable from the chronic mad.

The voices and presences of the patient, the prisoner and the lunatic are notably absent in the historical accounts that follow. Occasionally, as he went about his work an inspector would inquire into the well- being of a person as he or she passed in the hall. As the work of inspectors of prisons, asylums and other charities is described, the inhabitants can be imagined in the various buildings and cottages, going about their daily lives. They are referred to indirectly in reports, their bodies needing to be managed according to the problem or risk they are said to present or perpetuate. Risk management is at the root of preventative measures such as the separation of the young from the old, the curable from the chronic mad cases and the management of breeding.

The purpose of this chapter is to provide historical context and analysis for some of Ontario's early institutions and the implications of these for the present mental health system and those it impacts. From the middle of the nineteenth century to near the end of the twentieth

century, institutions were promoted as solutions for the custody, care and cure of people variously described as lunatics, imbeciles, idiots and habitual drunkards. The absolute silence of these people is palpable as the buildings and cottages in which they will be housed, imprisoned, punished, fed, exploited, abused, terrorized, clothed, hit, comforted, raped, treated and monitored are pragmatically if sometimes passionately discussed and debated.

Issues of concern at the time were those of health, social order and immigration. Calls from health ministers for more control over vaccinations and from inspectors of prisons, asylums and charities for more autonomy in institutional reform culminated in changes to legislative powers that had lasting impacts on health and immigration policy for Canada. Some of the threats, such as smallpox and tuberculosis were quite real, and the regulations were not unwarranted. For example, Dr. Peter Bryce, as "the first secretary of the Provincial Board of Health of Ontario, set up the first public health education exhibit about tuberculosis prevention in 1883 and drafted the Public Health Act of 1884" (First Nations Child and Family). Bryce is recognized as a person who "stood up for the safety, health and well-being of First Nations, Métis and Inuit children, even when it was a hard thing to do" (First Nations Child and Family). Other threats, such as the hereditary nature of madness and criminal behavior were not based on sound medical theory, but nonetheless, passed unchallenged into the myths of madness and class based theories of crime that was at the foundation of many institutions. A wide network of social reformers of this period worked toward establishing a clean, moral, predictable, organized society.

The sorting out process of types of people for whom each institution could potentially reform, correct or redeem was tightly woven to emerging eugenicist theories. The goals of the health ministers and those of the inspectors of prisons were often mutually aided by the same

discourses around people presumed to be potential threats. These aims were not at odds either with the ministers responsible for immigration. Archival data, specifically as these make visible discourses of madness, alongside race, culture and genetic predisposition to criminal behavior or madness as social problems in nineteenth century Ontario tether specific organizational events to more recent institutional histories. The stigma of madness was only exacerbated with eugenicist theories and with the increasing association of madness with the alienation and isolation of institutions.

By the middle of the twentieth century, it was widely accepted in the medical community that custodial care, or warehousing was really only justifiable in the most recalcitrant of cases—those cases that could not be ameliorated with the use of psychotropic drugs and those associated with danger and criminality and of course, the populations held in institutions such as the Huronia Regional Centre. The Huronia Centre, originally named the Idiot Asylum at Orillia came into existence as part of the wider institutional sorting process of the middle to late nineteenth century (Simmons 21). As Harvey Simmons explains in *From Asylum to Welfare*, asylums in Canada in the late nineteenth century were "completely integrated into the public sector" there was "no one whose sole interest was in the welfare of mentally ill and mentally retarded persons" (20). A further systemic danger common to all institutions, writes Simmons was that "the very presence of an inspectorate at the centre of the welfare net meant that policies attempted in one area would reverberate throughout the whole system" (21). Simmons' critical analyses of the work of female social reformers to protect the institution of the family and the resulting implications for those called feeble-minded who could very likely spend their lives in "closed systems" serving "the internal economy of the asylum" stands in sharp contrast to explanations provided by mental health agencies elsewhere (89, 105).

Where Simmons describes a vast industrial complex born out the marriage of eugenics, social reform, and economic interests, Ontario's Canadian Mental Health Association insists on describing its chief aim as that of continued deinstitutionalization and increasing access to community mental health services (Ontario CMHA). Indeed, even the recent settlement between the Ontario government and former residents of Huronia includes a general apology for mistreatment and abuses wrapped in a philosophical explanation of faulty perception (Ontario Ministry of Community and Social Services).

The peculiar machinery of Ontario's asylum system has been particularly effective at exploiting and exploring the bodies and the minds of specific individuals. Inmates of the Huronia institute, for example produced shoes, socks and uniforms for other institutions and were used to test experimental vaccines (Simmons 105-106). Indeed, the structures of some institutions were built by inmates themselves as part of a move toward moral treatment (Reaume *Remembrance* 133). As lawsuits such as the Huronia case and the Oakridge class action suit emerge, it is clear that Ontario's psychiatric history includes more than a misunderstanding over what it means to be mad or defective. Ontario's psychiatric history includes the strategic use of discourse and political power, with many profiting from the endless supply of institutional bodies. The present mental health system is considered as an historic trajectory of Ontario's psychiatric asylum and mental health history with attention to new forms of governing and *governmentality*. Essentially, this chapter considers the evolving gaze and its influence in the development of subjective experiences of being mad and getting help through mad services. This discussion is extended in the final chapter.

3.2 A Place for Everything: Ontario's Institutional History

Joseph Gusfield uses the example of drinking and driving as "a particular case" to inform "a more general case" (*Culture* 1). His book, he says, "is about culture—public meanings—and social structure—authority, control, and deviance" (1). Cars, says, Gusfield, are "microcosms on a large scale of the problems created by the conflict of restraint and release in American life" (1). What is significant about cars, says Gusfield, is that they require for their operation a certain level of skill, but, unlike planes and trains they are not "in the care of highly trained, paid, and certified personnel"(1). Gusfield uses the phenomenon of "the drinking-driving problem" to delineate the processes through which a social or private phenomenon evolves into a socially recognized public problem (3). Since the writing of Gusfield's book in 1981, the discourse on drinking and driving has evolved quite dramatically. It is hard to imagine a time when drinking and driving was an acceptable social behavior or when it was seen as a matter of personal choice. Everything about drinking and driving has changed since the time when it was excused such that even without recourse to law, we impose restrictions and offer alternative modes of transportation. We have in a sense become experts on the control of drunk driving behaviour through an authority that is not immediate, but taken for granted and immersed into social relationships.

A similar pathway has wrought other social phenomena out of private domains and private agreements into public discussion and debate. First through televised public service announcements and now through cyber debate, people can weigh in on issues such as partner violence, rape and drug abuse with an authority that comes from exposure to the issue, from having read about the issue and occasionally with reference to personal experience. Authority that is assumed and experiential represents a much larger portion than it did prior to widespread access to debates of social issues made possible through technologies of the digital era. In one

sense, this is precisely what activists and theorists have been after—a shift in the balance of knowledge and power. In another sense the era of the everyday expert presents a danger of a different sort; it is not that the emperor has no clothes, but that the laughing audience has not realized the full implications and the simple possibilities of reassembling knowledge mutually. It is a period of adjustment to be sure. For example, it is hard to go one day without hearing about someone's anxiety. Indeed, it is as common as a headache. It is not as common to hear about depression. Anxiety is often, but not always, spoken about in terms of busyness. Busy people talk about anxiety all the time and the fact that they are in the present, discussing it represents a triumph over it. The supposed other end of the mental health spectrum is not valorized in the same way—depression does not enjoy the same kind of social acceptance. Anxiety has, through some trajectory of authority imbued in those who speak of it come to enjoy social acceptance in the realm of the public domain as well as the private domain. Depression has not. Medically, both are regarded as points on the mental health scale, and socially they have meanings that are not openly acknowledged.

Madness presents a special type of problem—throughout history it has lacked a clear definition. At times throughout history, behaviours that came to be called madness were handled by families-for better or for worse. Madness came to be recognized nonetheless as a social problem, with various descriptors in the attempts by early settlers to organize institutions. One of the most influential of these people was John Woodburn Langmuir. Richard Splane, professor emeritus in the School of Social Work at the University of British Columbia, Vancouver, credits Langmuir with some of the most widespread reforms of institutions meant to regulate, reform and redeem criminals and people regarded as insane. "Year after year" writes Splane, "during his fourteen years as inspector, Langmuir presented superbly prepared proposals that won

governmental acceptance for new or enhanced programs in corrections and mental health, new facilities for the deaf and blind, and support and direction for a wide range of voluntary social welfare and health services under the Charity Aid Act" (Splane 210). Splane writes of Langmuir's use of British and American models in the administration of his duties. Langmuir also contributed to social welfare reform in his chairmanship of the 1890 Royal Commission on the Prison and Reformatory System, "a landmark endeavour in the history of social welfare" (Splane 210).

The year 1878 was fruitful and productive for John Langmuir. Langmuir's impact on social reform is impressive; his goals at the time were along the lines of making asylums and jails a better fit for the people they were meant to hold. He made distinctions between punishment and reformation; women and youth could be redeemed and reclaimed in specific institutions while men would no longer be left "languishing in idleness in local jails" (Oliver). Complementary to these goals was the establishment of methods of review that would ensure the least abuses of institutions and the most fiscally prudent use of government funding. That institutions themselves did not cross his horizon as a fundamental social ill does not necessarily render him narrow-sighted. Indeed, institutions themselves were quickly a taken- for- granted component of social order taking their cue, in Ontario, according to Langmuir, from the Commissioners of Lunacy in England (*Tenth* 12).

The uses of modern methods of statistical analysis to determine what kinds of people were filling up expensive asylums and populating the country were connected to the analysis of the types of people that were being allowed into the province only to make their way into the asylums. Mental illness, along with poverty, drunkenness and criminal behavior was viewed as an impediment to the otherwise robust project of settling the new nation; reformatory and

punitive institutions were promoted as solutions. In Ontario, as is shown in Langmuir's reference to the Commissioners of Lunacy in England, some tools and techniques to organize the residents of institutions were borrowed from the comparatively recent history of Victorian England. Social institutions became sites of inspection, and, continuing in the tradition of the Victorian period to which Langmuir alludes, they also became sites of correction and reformation. Dowbiggin has noted the significant influence of the eugenics movement in both the development of psychiatry and in nineteenth century immigration policy (*Keeping America Sane*). Social categories such as race, nationality, religion, gender, age and relationship to work were at the heart of the construction of some types of behavior as social problems to be treated and managed according to how these behaviours were interpreted.

The appearance of madness as a social problem cannot be determined in the same manner as the drinking driving problem. Neither institutions themselves nor societies invented as corollaries to their existence something to be called madness. Nor did madness, because it has always existed as part of the human condition, in the imagination and in the memory of the species, exist only as an idea. Rather madness is called madness only at particular times—when it interferes with other social functions. Institutions were built around the idea of madness. As more people were locked up, the problem appeared to be an epidemic and the evidence was overcrowding. Madness gradually became the corollary of increased institutions—in fact, it was not that more people were mad at the end of the nineteenth century, but that more people were perceived as mad.

By the mid-twentieth century, more specific mental health policies had replaced ambiguous governor's warrants, psychotropic medications were being used along with or in place of restraints and the *Diagnostic and Statistical Manual* of the American Psychiatric

Association was in its 3rd edition. “Negative critique of psychiatry,” write Shadia Kawa and James Giordano “mounted considerably during the 1960s and early to mid-1970s” (4). They note Thomas Szasz as being particularly influential in ushering in a growing skepticism for “the legitimacy of psychiatry as a medical discipline” (4). Kawa and Giordano draw from Milton Klerman’s edited collection to discuss the “lack of clear demarcations between mental health and illness, and the relatively low reliability of psychiatric diagnoses” which led to criticism both within and outside of the profession (qtd. in Kawa and Giordano, 4). But the DSM had not always been the subject of such criticism. Indeed, the first edition, the DSM-I, was an early nineteenth century attempt at classification of psychopathology based on “collections of demographic data by the Bureau of the Census” whose purpose was ”more for mental health policy to regulate the treatment of the institutionalized mentally ill, rather than for diagnostic purposes”. (Grob, qtd. in Kawa 2).

Despite criticisms, the APA’s flagship publication became a standard desktop reference text for diagnosis. “Referred to by clinicians from multiple schools, as well as by researchers, policy-makers, criminal courts, and third-party reimbursement entities,” write Kawa and Giordano, the text “enjoys a nearly hegemonic status … not only in the United States, but increasingly in Europe and more recently Asia ” (1). The influence of the DSM extended beyond professional use as lay people began to describe personality types, behavioural expectations and issues of the psyche born out of the 1960s cultural focus on expression and mind expansion; Freud, Kinsey and Erica Jong were not out of place alongside Andy Warhol and other sixties icons. A different kind of subculture existed in clinics and hospitals where clinical trials of psychotropic medications and behavioral control programs were being tried on students, military personnel and inpatients of psychiatric hospitals and training schools. Much of this history has

been disregarded as conspiracy theory nonsense but as psychiatric survivors began to tell their stories and as lawsuits continue to make claims for abuses against people held in institutions, the shadow side of Canada's psychiatric history cannot be denied. It is hoped that more Canadians will see justice through the legal system for harms done to them through lack of informed consent as well as through malice disregard and cruelty.

The past centuries of chaining, exploiting, experimenting and abusing selected groups of people may be accounted for in this century; it cannot be erased with recourse to caveats about the faulty epistemology of an era or the methodological errors of modernity. Ill-founded theories about genetics, race, gender and intelligence go some way toward explaining so many trials, treatments and experiments, but at the root and heart of these were the places and spaces where these occurred; once the institutions were built and filled, theories about the best custody and cure were expected of the superintendents and alienists who ran them.

Governing the microcosms that were institutions began with a series of decisions about the governing of the province of Ontario. This pivotal era of cost analysis, risk assessment, special threats to the new colonies had implications for the treatment of mad people for more than a century, implications that can be understood in the present more clearly by looking back at the past. The madman, the Down's syndrome child, the blind were among the people whose lives, it was thought, had to be managed and controlled. Through the discourses of the multiple dangers such people presented to the species and to the economy, an early neoliberal discourse, they were allowed to live, but only just, in Agamben's sense of bare life (*Homo Sacer: Sovereign Power and Bare Life*). With advanced technologies and a more precise analysis of risk, even that is removed.

The goals of immigration and social reform intersected at specific points in Ontario's history to create and justify the bedrock upon which the present mental health system was built; multiple forms of management and control grew far beyond the tangible structure of the asylum system to fill different places and spaces in contemporary mental health landscape. Madness is now everywhere, not to be feared or kept in the shadows; people diagnose it in themselves and others with the language disseminated by medical professionals, researchers and bloggers. Madness is simply a disagreement of perception.

In 1878 Langmuir had held his position for about ten years, having been appointed as inspector of prisons, asylums and public charities in 1868. As Oliver notes, the *British North America Act,* 1867 saw increasing welfare responsibilities for the provinces (Oliver). In his biography of Langmuir, Oliver writes, "Before 1867, the board for prisons, asylums and public charities was composed of up to five inspectors, but the new act allowed for just one person, who would be paid about one-third less than they had been" (Oliver). Oliver refers to these years as "the critical years when the new province was developing its policies in social welfare and was establishing new institutions while reforming others (Oliver). Among the inspector's "formidable responsibilities" was the preparation of "full statistical returns" for "changes and improvements", the framing of by-laws and financial statements and supervision of "the construction of new jails and the renovation of old ones" (Oliver). The inspector would "oversee institutions falling fully under provincial control (notably asylums for the mentally ill), those privately controlled but receiving some provincial funding (such as poorhouses and hospitals), and those under shared jurisdictions (mainly local jails and lock-ups)" (Oliver).

Labour in many forms existed in every institution but in 1871, with the an *Act to provide for establishment of a Central Prison for the Province of Ontario* only recently established,

external contracts were suggested for "the lease of the prisoner labour" (Langmuir *Fifth* 1-2). In his fifth annual report, Langmuir suggests that the problems he will outline and attempt to remedy in this report are " the very crude and ill-defined method of granting Government aid to Hospitals and Charitable Institutions" as well as the history and present state of "the industrial employment of the prisoner" and, following examples of "the efforts of Governments and philanthropists of the United States and Great Britain to reclaim inebriates", he will describe what he has found out about the state of inebriate asylums and their methods of treatment (*Fifth* 1-2). Lastly, Langmuir notes the present state of the insane, pronouncing a "scheme to provide increased accommodation" which will satisfy the mutual aims of a province which will not "suffer her insane to be neglected" while avoiding the building of new asylums (*Fifth* 2).

Langmuir did not see insanity as being more likely in people of particular nations or religions. Indeed, warned Langmuir, figures telling the nationalities and religions of those kept in institutions could be "grossly misapplied" when issues of "poverty, intemperance, physical diseases, losses, and hereditary taint" were more predictive of insanity than the chances of birth (*Fifth* 6). He calls attention to the warrant system of transfer, wherein, prisoners established as insane and dangerous to be at large are processed first through the prison system and then transferred to the asylums, noting, through analysis of discharges, that the "curative character" of the asylums has not been affected by the admission of "the great number of chronic and incurable to its wards" (Langmuir *Fifth* 8).

Notwithstanding the neutral effect of warrant admission on the hospital character of asylums, Langmuir calls for a more robust process of admission generally, noting that the present system, allows for "quite harmless imbecile vagrants" and on occasion "the victim of a continued drunken debauch" pronounced by often unskilled Magistrates as "dangerous Lunatics" or

"convicted of *lunacy*" respectively (*Fifth* 9). In three concise points, Langmuir lays out a plan for increased investigation into the personal and family history prior to admission to jail in the first place, remuneration of any possible financial support from families of people committed to asylums and a suggested course of treatment per the jail surgeon as well as specific reasons, as corroborated by two Magistrates (*Fifth* 9).

Toward the aim of more efficient means of using government funds, Langmuir proposed the establishment of an asylum for inebriates. Calling attention to the moneys "derived from licenses for the sale of liquor, *and paid into the Provincial Treasury*", Langmuir notes that it is only right that some of this money be directed toward "a plan of treating drunkenness as a *disease* and of establishing hospitals for its cure or amelioration" (*Fifth* 35). Through skilled analyses of patient and prisoner statistics and costs and savings of each asylum as they existed in 1871-1872, Langmuir had effected a separation between cases that required custodial management and cases that could be worked toward a cure. He had also accomplished a secondary effect of establishing rational methods for the rigorous but fair treatment of all the province's wards, essentially delivering the government's institutions, including its asylums, from its chaotic and random pre-modern history. Langmuir was most efficient at convincing government of the duty it held and of the responsibility he and they had to the public; this concern had the effect also of producing and sustaining a discourse around public problems such as drunkenness, madness and crime. At the critical juncture of the establishment of an inebriate asylum, Langmuir cites drunkenness as at the heart of most public problems, drawing a connection between the moneys taken in on account of liquor sales and the moneys that should go out toward the redemption of those for whom government regulations are not enough to preclude excessive consumption. Langmuir's suggestion for the establishment of a more humane

approach to drunkenness claiming that "the plan of treating drunkenness as a *disease* and of establishing hospitals for its cure or amelioration is not chimerical or impracticable" set the course for social reform toward specialization and a focus on the pragmatic use of bodies according to their ability and medical state (*Fifth* 35). Habitual drunkenness was regarded in this scheme as one condition that could and should be treated with compassion rather than punishment, its proper cure lying at the heart of the eradication of many other public problems and a medical approach offering a rebranding of asylums and institutions and, by extension, the men in charge of them.

> And last of all the establishment and maintenance of an Asylum of this character falls within the true sphere and work of the Government. It would be pre-eminently an institution of *public utility*, as the evil against which it would contend is pre-eminently a public burden and calamity. The degree of disease, idiocy, insanity and crime directly and indirectly caused by drunkenness, and the extent of the pecuniary expenditure out of the public funds together with the decrease and limitation of the general wealth thus occasioned are simply incalculable. (Langmuir 35)

In his ninth report, submitted a few years later, Langmuir draws attention to the increasing need of "Asylum accommodation for insane and idiotic persons" and as well continues to underline the necessity of approaches specific to each institutional population (*Ninth* 1). Specifically, Langmuir had been effective in having the Inebriate Asylum at Hamilton transformed into an Asylum for Insane as well as converting "the buildings at Orillia into an Asylum for Idiots" (1). This had the effect of allowing those held in jails to be removed and placed into asylums. Langmuir explains that a further distinction is of necessity made between those insane of a "chronic and mild character" and those who are more violent, the latter being ill-suited for the

structure of the asylum at Hamilton (1). Thus began a long process of sorting and categorizing the mad, the poor, the drunkards and the idle according to the problems they were assumed to pose and their potential for redemption. Madness in particular, thought Langmuir, should not be allowed to languish without treatment as "neglect, or lack of proper treatment rendered it [insanity] in many instances chronic and incurable" (*Ninth* 2).

With the successful transition of the asylum for inebriates into an asylum for "chronic cases of a mild character" these being selected from the populations of asylums in Toronto, Kingston and London, those who had been "long under surveillance" and "known to possess no dangerous proclivities", Langmuir underlines the importance of specialized treatment and timely intervention (*Ninth 2*). The "chronic and incurable" cases can be reduced through an asylum system that was not, but should be "rather in advance of…the possible demands made upon it" (*Ninth* 2). Citing the 1877 census returns, Langmuir highlights the statistical average of "one person of unsound mind to every 397 of the population" and the alarming shortage of beds represented in the province's capacity to provide for only "one if every 909 of the population" a situation that has been ameliorated to a capacity of "one in 810" with the changes of the years prior to Langmuir's ninth report (*Ninth* 2).

Throughout his career as inspector, Langmuir insisted on the prudent use of government resources as well as the establishment of methods of assessing government expenditure in the province's institutions. In his tenth report, Langmuir refers to the Act of Confederation of 1867 which placed institutions (asylums, prisons, reformatories and public charities) under the power of the province of Ontario and gave the province "the privilege of founding and organizing such Institutions as are actually required, and just at the time when required, for the care, treatment and relief of her mental, physical and moral defectives, without having to consult the wishes, or

wait the action of a neighbouring Province"(*Tenth* 1-2). Langmuir wrote triumphantly of this pivotal era of Ontario's history, convinced that the right to build institutions whenever necessary would provide a financially sound solution to a class of people he is convinced are in need of some sort of management.

Where his earlier reports had called for care over custody and redemption over punishment, his latter reports draw attention to the alarming increase and expense of commitment. He looks to experts on crime to explain its presence and prevalence in certain classes of the general population, noting the "unprecedented increase in the commitment of the vicious, depraved and vagabond classes, generally known as vagrants and tramps" (*Tenth* 4). He sought methods of ameliorating the outgoing resources and increasing incoming profits. To this end prison labour was taken up in an attempt to bring in money and the practice was also lauded as a sound method of punishment and correction. "So far as able bodied men of this class are concerned," writes Langmuir, "it is clear that enforced labour and tasks of the hardest and most menial kind, carried on with within the jail walls or in the public streets and highways, are the only way of stamping out this evil… the sooner the municipal authorities take the matter in hand, the better" (*Tenth* 4). Langmuir saw the potential for the prison system to serve as "a correctional institution and an industrial reformatory" (*Tenth* 4).

As a solution to overcrowding, Langmuir proposed "…a scheme for the addition of 850 beds to the Asylum accommodation of the Province" (*Tenth* 7). Among the suggestions were expansions at the Hamilton and London asylums, the acquisition of the Rockwood Asylum, provisions for a (new) Medical Superintendent at the Toronto Asylum and a training school for the Asylum for Idiots at Orillia (*Tenth* 7). Referring to the public burden of caring for those who "were not proper subjects for asylum treatment", Langmuir suggests that these people could have

been and should have been cared for locally in private houses at a much lesser cost to the institutional system. He calls for stricter measures for committal, noting that inquiry into the process "is frequently neglected, or the information given is of the vaguest character" (*Tenth* 11).

Langmuir continued to emphasize the necessity of reliance on prudent, rational, legal processes of committal. He coupled this with a growing scientific approach to the causes of criminality and insanity, a project he continued as chair of the 1891 Commission. He was firmly situated at the helm of late nineteenth century social reform, a ship whose sails were fastened to the application of scientific methods of social control and regulation. From this position, the institutional system that began as a response to wandering mad men, mad women, vagrants and thieves, emerged as the locus of a thing called madness, as its expert vantage point, and as the producer of knowledge about mad people.

In 1881, in his last year as inspector, a second inspector, William T. O'Reilly was hired to assist Langmuir (Splane 51). O'Reilly's reports show a continuation of the sorting of people into institutions for which the institutions were intended as well as a continued need for room for the "many private applications which could not be entertained as well as the several insane persons confined in Gaols" (*Fifteenth* 3). As inspector of prisons, asylums and, public charities, O'Reilly continued to report on the movement of inmates, the work projects and new buildings and he continued to call also for proper accommodation.

The legal framework underpinning the duties and privileges of the inspectors, as noted by Splane, was the *Prison and Asylum Inspection Act* (44). This act "was to stand throughout the period as the basic definition of provincial responsibility for social welfare" and its focus was "about half…concerned with corrections" with broad powers extended to the inspector "in respect to the mental institutions" (44). O'Reilly's focus, from 1881 until he died in 1890 had

been “mainly with the institutions in the health field” and he shared the duties of inspector with Robert Christie who “assumed the principal responsibility for the correctional institutions and for the inspection of the houses of refuge and the orphan and Magdalen asylums” (Splane 51-52).

From the appointment of two inspectors on the reports reflected “a cleavage which…until 1881, had been viewed as a single field” (Splane 52). The cleavage to which Splane refers is reflected in the reports which from then on were divided into six reports dealing with “the asylums for the insane and the asylum for idiots, the common gaols, prisons, and reformatories, the Ontario Institution for the Education and Instruction of the Deaf and Dumb, Belleville, the Ontario Institution for the Education and Instruction of the Blind, Brantford, the hospitals, the houses of refuge and orphan and Magdalen asylums” (52).

By 1890, the “lack of strong social welfare leadership from the office of the inspector of prisons, asylums and public charities…encouraged leadership to emerge from other quarters” (Splane 54). Although Langmuir’s exceptional work would have been hard to follow, the lack of leadership referred to can be attributed less to any deficit on O’Reilly’s part, and more to the chief loss resulting from the division of social welfare administration such that “the many social welfare programmes which were combined in the office would no longer be viewed in their entirety” (52). The division of administrative labour effectively saw correctional work flow in one direction and that of charities, asylums and institutions in another; a distinctly punitive model is evident in the report of the Royal Commission, a post which Langmuir had been assigned in large part due to his years as inspector but also because he had become “as respected leader in the business community” (Splane 55).

The purpose of the Royal Commission of 1890 was to investigate causes of crime, to consider improvement as regards industrial schools, to rescue "destitute children from a criminal career" (Commissioners 5). The committee aimed toward improvement in the classification process of jail and the "fitting practical employment of prisoners" and looked for "improved way of dealing with tramps and habitual drunkards" and as well the "question of indeterminate sentences for offenders against Provincial laws" (Commissioners 5). Such an inquiry into the causes of crime showcased the modern method of statistical analysis as well as the potential for social reformers to engage in more compassionate, charitable work through less visibly punitive institutions. The appearance of a rational process of institutional management reflected a move out of the savagery and barbarism of old methods of management.

The committee sought out people considered experts in law and crime and in the scientific management of prisons and penal institutions (Commissioners 6). Among these were Sir James F. Stephen, Sanford M. Green and Havelock Ellis. Stephen, "a high authority in his history of the Criminal Law of England" claimed that crime could be defined as "any act or omission punishable by law" but that "criminal law must…be far narrower than morality" and that such "vices" as require a broader definition "are in many cases the root or germs of the greater offences called crimes" (Stephen qtd. Commissioners 35). For his part, Green, a judge who had published on the subject of causes for and treatments of crime vowed "not to be limited to what the law treats as crime" but to include also "all wrongs committed against persons or property, public health, justice, decency and morality, whether forbidden by law or not" (Green qtd. in Commissioners 35). Where Stephen suggests a rooted viciousness at the base of "many cases" of crime, Green oversteps chance and law altogether in his sweeping definition of what constitutes crime.

Ellis was regarded as an expert on the classification of the criminal. It was his opinion that "there are some naturally more prone to crime and more devoid of guiding and inhibiting instincts than the generality of mankind" (Ellis qtd. in Commissioners 35). Ellis continues, "Sometimes a generation of criminals is merely one stage in the progressive degeneration of a family. Sometimes crime seems to be the method by which the degenerating organism seeks to escape from an insane taint of the parents" (Ellis qtd. in Commissioners 35). Ellis had recently published his book, *The Criminal*, a work meant to deal with "the problems connected with the criminal as he is in himself and as he becomes in contact with society" (Preface). At this juncture in reform history, the emphasis is on the troubling rather than the troubled subject. Questions as to how institutionalization was experienced subjectively were an impossibility until voices began to speak from the institutions; we know of course that they always did, but in a peculiar epistemological turn they were often interpreted as *indications* of madness, given the location from where they came.

The inquiry was meant to be sweeping and broad, calling not only on the experts noted above, but as well a review of "the best known institutions of the United States" (Commissioners 6). Before proceeding with the general provincial institutions, the commissioners were given authority to visit penal and reformatory systems in Massachusetts, New York, Michigan and Ohio, as well as obtaining copies of the reports and "such information respecting the management of the principal penal establishments in Great Britain & Ireland, and other European countries as could be obtained" (Commissioners 6). It was decided also that "the Chairman should put together a series of questions to be put to such witnesses as might appear before the Commission" (Commissioners 6). The commissioners invited the input of interested members of

the public in forums held in Toronto, Hamilton, Kingston, London and Ottawa. Notice to attend and participate was given through the press (Commissioners 6)

The questions posed were specific to the witnesses. Jailers were questioned in regard to their experience, and to the structure of their particular prison as well as to the status and characteristics of those held in their prison. On this last point, the questions inquired into the gender and age of the prisoners as well as length of time they tended to spend awaiting trial and what were the opportunities available to them to mix with other prisoners (Commissioners 7). Langmuir's interest in wasted or idle time can be gleaned here as well as the notion of the element of contagion that crime was seen to carry. The line of inquiry was also specifically directed to the mixing of lunatics and imbeciles with the general prison population and the potential of separation of various classes of prisoners under the then present structure (Commissioners 7). Another set of questions addresses the issue of habitual drunkards. Witnesses are asked if these might not be better suited in institutions which would "reclaim any considerable number of gaol drunkards" (Commissioners 9). Other questions the commissioners asked leaned toward reclamation where possible in the case of habitual drunkards and prevention in the case of "young persons showing a tendency to crime from destitution, vicious dispositions, evil influences, parental neglect, or other causes"(9).

Langmuir concluded the 1890 Royal Commission with specific recommendations. Among these are suggestions for the provision of sanatoria and reformatories for those "given over to habits of intemperance so as to render them unable to control themselves, and incapable of managing their own affairs" (Commissioners 37). The recommendations also included a schedule of inspections by a committee, which included a doctor, and the establishment of a workhouse within the reformatory. Attention was given to the money paid to the habitual

drunkard who would find himself in one of these workhouses. His earned money would go first to pay for his keep and anything left over would go to his wife and family.

The work of the Royal Commission was made public through the press. The sessions presented an opportunity for people who thought they had some insight into the subject of crime to make this known. Public notices of the time and places of the sessions in Toronto, Hamilton, Kingston, Ottawa and London invited "all persons interested" to come forth and "state their views" on the matter of crime (Commissioners 6). Officials such as sheriffs, jail managers were specifically invited to "be present…and give evidence" (Commissioners 6). As well, the extent and breadth of the institutional system, in Canada and in the United States is made visible through the report which details every reformatory, prison, industrial school, lunatic asylum, penitentiary, jail and house of correction that the committee visited (Commissioners 14-15).

The study of crime was given special attention during this time. Noted experts addressed a widely growing concern for what was to be believed to be the hereditary nature of crime. The duality of crime, it was thought, was such that it could be *caught* by association with criminals and through genetic taint. That so many institutions contained so many forms of criminality would seem to address its rootedness in all forms of deviance from pure progeny and its tendency to show up in habit and in somatic form. *Reformation* then, at every level of the human, from creation to soul and all noble attempts at pivoting the body and the mind in the correct direction work in which could be witnessed the redeemer and the redeemed. That religious observations were a feature of reform work is notable in the reference to prayer and attendance at chapel in several of the visits to institutions undertaken by the committee. Beyond the religious impetus, there was, as Splane notes, an increasing sense of social responsibility. "The problems

which it examined", writes Splane, "could not…be regarded solely as a product of the failure or weakness of the individual" (56).

Langmuir's reform work makes visible the subtle widening of what were at first, before the dramatic influences of the industrial era of which institutions were part and parcel, only gaps. The mad, the odd, the slow had always existed and families had their own, often, but not always, cruel, ways to deal with such people. With increased populations came increased social visibility and informal gazing and sorting. Institutions rendered this process formal, scientific and eventually medical. The distance created between people of the same species, through sanctioning specific places for those who posed as threats, was not by chance. In the same way that contagious diseases could be "caught", any association with madness had to be noted and accounted for. The mad, now safely tucked away or locked away, depending on whether one saw madness as something to be cured or punished, had to be distanced from the rest of the population. The distinction between the two quite disparate goals of cure and of custody heralded the medical era of madness. Cure could come about, it was suggested through scientific approaches in its early stages of madness and custody, in chronic cases, relied on good institutional management

Other issues that were brought into public discussion through the Royal Commission were questions as to what should be private and what should be public responsibilities (Splane 56). That such questions became bureaucratic quarrels, most notably between asylum doctors is noted by Dowbiggin. Dowbiggin points to more self-interested agendas as being behind the fervor with which many physicians pushed for more government responsibility for public health. With the push toward more public responsibility it was hoped that more public funding would follow. Lunatics and their management as patients, it was increasingly recognized, could prove

to be a lucrative source of revenue. “In Toronto,” Dowbiggin writes in *Keeping America Sane*, “the physicians Peter Bryce, Charles Hodgetts, J.W.S. McCullough, Helen MacMurchy, and Charles Hastings were the chief crusaders” for increased government responsibility in public health (135). The other side of this was that preventive medicine as advocated by more government involvement and the instructive advice of public health programs, might pose a threat to “curative medicine and reduce the flow of patients into physicians’ offices” (Dowbiggin136).

The distinction between custodial care facilities and between cure and prevention, a responsibility characterized by MacMurchy as “the burden of the good citizen,” marked two very different philosophies of care and two very different political approaches (qtd. in Dowbiggin, 164). The distinction was outlined also by increasingly imagined potentially degenerative immigrants. As Dowbiggin notes, “When poverty-stricken men, women, and children from central and eastern Europe and the slums of British cities had begun disembarking in the late 1890s, Canadians’ fears about ‘race suicide’ had escalated” (Dowbiggin 137). Referring to Canadian psychiatrists of the late nineteenth to early twentieth century period, Dowbiggin writes: “Soon they began alleging that foreign-born patients were disproportionately represented in public asylums and that this was due principally to immigrants’ hereditary defectiveness” (138).

This idea was promoted by another speech given by T.W. Burgess. In San Antonio, Texas on April 18, 1905, T. W. Burgess, by this time president of the American Medico-Psychological Association, notes in his speech to the assembled body of psychiatrists a continuation of the tradition of Canadian members to serve in the capacity of president of the American foundational organization (“Insane”). Burgess had been interested in “promoting psychiatry as a medical specialty” and in advancing what inroads had been made toward this

goal by forming such societies of alienists as the Société Médico-Psycholgique de Québec, becoming its first vice-president and in 1899 its president (Grenier). Ambition and curiosity, two traits in rich supply in Burgess were especially lauded in psychiatry, a specialty that has had to fight for its place in medicine since its beginnings.

Burgess' career was nothing short of stellar and his promotion of psychiatry was pivotal to the establishment of psychiatry as an industry of institutional care and dissemination of psychiatric knowledge. After organizing in 1902 the meeting of the American Medico-Psychological Association, formerly the Association of Medical Superintendents of American Institutions for the Insane, he became in 1904-05 its third Canadian president "after Daniel Clarke in 1891-92…and Bucke in1897-98. As well Burgess established a footing for psychiatry as a "medical specialty" by providing lectures at McGill University (Grenier). Burgess has established for himself a reputation as "being the first to devote himself to the history of psychiatric institutions in Canada" which incited a 1913 invitation "to write the Canadian Section of a book entitled *The institutional care of the insane in the Unites States and Canada…*published in Baltimore, Md, in 1916 and 1917" (Grenier). In a chapter called "Immigration as a factor in the increase of insanity", Dr. Foster Pratt is quoted by the group of authors, which included Burgess, as giving "the first declaration on the subject of restrictive immigration legislation by the Association of Medical Superintendents of American Institutions for the Insane" (Hurd 354). Pratt, from Kalamazoo, had introduced "at the thirty-eighth annual meeting of the Association in Philadelphia, in May, 1884" a "series of resolutions" which were "unanimously adopted" (Hurd 354). The resolutions, based on "the eighth, ninth and tenth censuses" appeared to show an increase in "the proportion of insane to the total population" as well as "a large defective element found among the 'foreign born' who [have] emigrated [to us]

since 1847 and 1848" constituting "one-eighth of [our] total population" but "approximately, one-third of our criminals, one-third of our paupers, and one-third of our insane" (Pratt qtd. in Hurd 355-356).

Among Burgess' contributions to the book was a detailed history of pre-institutional care of "indigent patients, the crippled and idiots" beginning in 1639 with the establishment of the Hotel Dieu in Quebec by Duchess d'Aiguillon and the Hotel Dieu which was founded by Mademoiselle Mance in 1643 (Burgess "Care", 446). Burgess concludes in his history that "the first care of the insane in North America was undertaken by the religious bodies of New France, now Quebec" ("Care", 446). By early nineteenth century, Burgess further concludes, based on an 1824 special committee report of the Legislative Council of Lower Canada the insane suffered "the wretchedness and misery of the surroundings of the insane in the early hospitals" ("Care", 446).

Burgess was also, in 1918, "a member of the Canadian National Committee for Mental Hygiene, whose objective were to identify the various segments of the population that showed a high risk of mental illness, to organize research on the functioning of the brain and nervous system, and to conduct public information campaigns about insanity and ways of avoiding it" (Grenier). Burgess' lectures and presentations were effective in establishing the institutionalization of the insane in Canada by presenting an image of them to be pitied, but equally guarded against through the promotion of a national idea of genetic scrutiny, or eugenics.

The promotion of scientific ideas effectively aligned alienism or psychiatry with other health concerns aimed also at protecting the country from public health concerns, through education and instruction of free citizens and confinement and correction of poor people, those unable to work, insane people and people whose race or religion were thought to exacerbate the

national hygiene movement. Medicine had established formal authority through a similar trajectory of promotion of public concerns and through the dissemination of information relating to specific and immediate public threats. Peter Bryce reviews the purposes of an *Act to establish a Provincial Board of Health*, and to give increased powers to Local Boards of Health (letters capitalized in the original text). Bryce includes a full copy of the Act, to be called the *Public Health Act*, 1882 ("Appendix A"). The main purpose of the act was to establish structure and responsibilities with the establishment of the Act (Bryce, "Appendix A" 1-4). The board would be responsible for disseminating "information relating to the prevention and spread of contagious and infectious diseases through the medium of the public press" and as well would be responsible to investigate epidemics and respond to the outbreak of "small-pox or any other disease dangerous to the public health" by isolating threats and posting notices "that such disease is within the said house or dwelling" (Bryce, "Appendix A", 3). In 1883, the Provincial Board of Health presented its First Annual Report, including a copy of an *Act to establish a Provincial Board of Health* and to give increased powers to Local Boards of Health ("Appendix A",). The establishment of a central health board in Ontario was being considered in 1877, influenced by the "devastating scourge of yellow fever" in the United States (Bryce 9). Still unsure as to how to approach contagious and therefore preventable disease, several of the states were pushing for establishment of local health boards. What they needed to move this process along was scientific authority. "What was wanted everywhere," suggests Bryce, in his secretarial report, "was scientific authority for the measures they (the boards) advised" (10).

It was easy enough to see the cause for alarm and the call for more authority. Bryce and his health board colleagues, part of the original patriarchy, were the appointed stewards of the health and hygiene of a nation with all the responsibility that these positions entailed. The report

of the secretary as outlined in the list of contents of the twenty-first report to the board of health for 1902 covers epidemics of cholera in Ontario, as well as research and discoveries of germs and bacilli thought responsible for diphtheria, rabies, foot and mouth disease, cholera, plague, malaria and yellow fever (Ontario Dept. of Health, Contents). As secretary of the board, it was Bryce's responsibility to report on the state of health as concerned the noted threats across Ontario. He included also a review of the history of epidemiology in Ontario, referencing an 1891 report of the board which pointed out that "as early as 1832, a medical examining and licensing board existed in the Province, but there is no evidence to show or lead us to believe that any teaching of sanitary science was a part of the requirements of physicians" ("Part I, Report", 8). The case to which Bryce refers in his report was that of an outbreak of what was thought to be typhus or typhoid, and the alarm with which Bryce's colleagues before him had reacted to the situation. Quoting "a report made in 1832 by the Legislature of the York (Toronto) Hospital and Dispensary", Bryce draws attention to the pre-scientific perspective which blamed the outbreak on the " 'misery and wretchedness of lower classes of emigrants' " and the more scientific findings of Jenner in 1849 ("Part I, Report", 8). Following Jenner, whose work led to "the final distinction between these two diseases", the "infectious nature" of what was discovered to be enteric fever, as well as "its propagation" in cities led finally to the discovery, after establishment of a board of health, of a particular bacillus. ("Part I, Report", 8).

When it was discovered that diseases could be caught and spread, it followed that they could be contained through actions deemed appropriate by the board of health. This had been the case, claimed Bryce, during the cholera outbreak of 1832 in Lower Canada ("Part I, Report", 9). In describing the evolution of public health, Bryce traces both the difficulty in having the board established as a legitimate entity, its existence threatened between bouts of epidemics, and he

emphasizes a broader goal of establishing boards of health as watch-guards over a public who could easily forget the threats of rabies, tetanus, smallpox, typhoid, plague and cholera ("Part I, Report", 13-16). Bryce revisits each of these diseases and the scientific approach applied through the discovery of the nature of disease which resulted in some cases in the use of vaccination (smallpox was an early candidate for this approach) and in other cases, isolation of suspected pathogens. ("Part I, Report", 13-16). In a nod to the extensiveness of the work of the board of health over twenty years, Bryce notes the work of "a Japanese student of the Hygienic Institute of Berlin" as well as "the work of Manson and Ross" in discovering treatments for plague and for malaria respectively ("Part I, Report", 16-17).

In concluding the review of epidemics, their causes and conditions and measures taken by the board of health, Bryce states, "these several references to the discoveries made during the past twenty years, regarding the causes of diseases, have, as already remarked, been the basis upon which exact regulations for the suppression of the several diseases have become more possible" ("Part I, Report", 17). Tuberculosis, however, remained "that most fatal of the diseases in temperate climates" and a threat to those afflicted, "now retrograding and deceiving by raising hopes…yet seldom failing in the end to make its last thrust fatal".("Part I, Report", 18). Tuberculosis, due to the "difficulty in the institution of practical measures for its suppression" and the subsequent necessary "measures to be taken" had Bryce considering the lengths to which the responsibility of the board of health should reasonably and ethically extend ("Part I, Report", 18).

Some of the complications of tuberculosis, as Bryce saw the situation were not wholly unlike those of insanity as Langmuir had assessed that condition. Like insanity, tuberculosis was problematic in its scope, its expense and in "the intimate relation of the disease to individual

habits" some of which, thought Bryce were social customs while others had a relationship to what he called "industrial methods". ("Part I, Report", 18). Bryce's portentous and philosophical musing at the end of his report suggests cryptically that the board of health is responsible beyond complicity of the sick and that "some day (sic), somewhere, somehow, there will yet be those who…shall be able to say…for I know that I have done good to the sons of men, and that they honor [we] who [have] saved them from cold, and hunger and sickness. ("Part I, Report", 18).

The similarity between these two conditions, insanity and tuberculosis, did not end with the analyses of Bryce and Langmuir's respective research into the causes and conditions of his respective specialty. Isolation and specialized institutional care, as called for in Langmuir's assessment of the state of insanity, was the remedy also for tuberculosis. Fresh air, exercise, and rest were the general and rigorously applied recommendations for tuberculosis along with a widespread public awareness campaign. In 1902 the Muskoka Free Hospital for Consumptives, originally a cottage sanatorium opened in 1897, opened its doors to aid "people in the early stages of lung disease" (Ontario. Ministry of Government and Consumer Services). Custodial or palliative care were not even considered in later stages. People with "advanced cases were refused or sent home" while the patients who remained were subjected to rigorous fresh air, "10 to 12 hours of each day in the open air, regardless of the weather" (Ontario. Ministry of Government and Consumer Services *Tuberculosis*).

A national hygiene movement in health promoted bucolic images of fresh air and personal discipline in contrast to the dirty conditions of city living and industry. Institutions could provide the former in the form of asylums and specialized hospitals for those with treatable insanity or tuberculosis. From within and outside of such hospitals and institutions, especially since the discovery of tuberculosis, ongoing preventive measures and risk assessments became

part and parcel of dealing with the public problems of illness and insanity, and this included increasingly intrusive biological surveillance of the greater public for increasingly nationalistic ideas of the greater good.

In considering the history of social welfare in Ontario, Richard Splane suggests that social problems co-occurred with progress. Splane argues that "the pace of advance prior to Confederation had, moreover, been accelerating as the wealth of the province increased…and as increasing population and the growth of towns and cities caused an intensification of the social problems that required action" (6). Splane offers no definition here of social problems, but he does expand on "the story of industrial growth" as "told in the shift of population from the countryside to the towns and cities, particularly between 1881-1891" (8). Splane's graphs show a population increase provincially of 10% with a corresponding increase of 23% in "those cities and towns which in the latter year had over five thousand residents" (8). Cities such as Toronto, Kingston, and Sarnia show increases at 88.4%, 36.7%, and 72.7% respectively (8).

As Dowbiggin makes clear in *Keeping America Sane*, the careers of late nineteenth century psychiatrists, such as C.K. Clarke and George Alder Blumer, were from the beginning intertwined with personal goals and with the new science of eugenics. Dowbiggin argues that the professional interests of those involved came to determine what would become of eugenics. Dowbiggin is particularly interested in "the mental processes" of Blumer, who was "head psychiatrist of the Butler Hospital in Providence, Rhode Island, one of the best-known mental hospitals on either side of the Atlantic Ocean" (*Keeping America Sane* viii). Dowbiggin was interested in the mental processes by which Alder had moved "from being a convinced eugenicist to an anti-eugenicist" (*Keeping America Sane* viii), and thought that by looking

through Alders' unpublished papers he could understand the extent of the persuasion of eugenics. It was this research that led Dowbiggin to the work of C. K. Clarke and others.

3.3 Local Madness

A black and white photograph of the C.P.R. Tote Road into Sudbury, taken some time in 1883, depicts a narrow, winding path in a heavily wooded area (Howey 49). Recently, I hiked through similar woodlands surrounding Sudbury. A surprisingly little known forest, Wolf Lake Old Growth Forest Reserve is accessible within a couple of hours by car and then on foot or bike. On a few occasions I have temporarily lost my way on some of the roads and paths in the surrounding forest, shaking my head and blinking my eyes to avoid the encroaching panic which so often results in a mad dash for some imposter of escape and then—the possibility of being seriously lost. I have often wondered, in the moment of my breathing's return to normal at something familiar, what it must have been like for the first settlers. There is nothing here to offer comfort or escape from this mad and beautiful wilderness. Less possibility of the appearance of either comfort or escape would be present in the earliest days of Sudbury's newest settlers. The comfort of familiarity, camaraderie and the establishment were among the projects of priority in Sudbury's early days as the new residents took up their own sorting out process.

In meeting her husband for the first time, one of Sudbury's notable early historians is "shocked, horrified" to see her new husband in the "very latest style of sport costume, which consisted of almost nothing" (Howey 7). Settlers like the Howeys came to Canada and to what is now called Sudbury from all over the world with hopes of finding work or buying land. Among the first social needs to be identified and addressed were the medical and spiritual needs.

Historian Frank Peake provides an excerpt from a letter written by one of the first Anglican priest in Sudbury, Reverend Charles Piercy:

> Sudbury is now [1891] recognized as the labour centre for the large mining and lumber industries in operation in this part of the Province of Ontario. Here find their way the great majority of cases requiring medical and surgical treatment-some very distressing-which have come under the observation of the officers of the municipality, the medical profession and the clergy, as well as the citizens generally. The absolute necessity for a hospital at this point is forced upon us. Such an institution situated here would be accessible by the main line of the C.P.R. and by the Sault Ste. Marie branch of the same railroad. (Peake 8)

Proximity to an asylum or Ontario hospital was likely a factor in the decision to keep a person at home or have them committed. The possibility of visiting a person would have been substantially more difficult for one who had to travel a long distance. It would have been a difficult decision for someone from Northern Ontario to commit their loved one to an institution many miles away. Given the distance, the climate, and the available transportation, the only way to communicate regularly would be to write letters. The 1891 Census for McKim contains names of those who were sent from home to an institution and those who were maintained in institutions. Out of these records emerges one story that is perhaps representative of the special difficulties faced by settlers with little family support.

Robin was a young woman living in Sudbury at the end of the nineteenth century. She might have been having a similar experience as Florence Howey was having twenty years earlier. Perhaps she was making friends and establishing herself in the growing community. One day, a few years prior to 1893, as the niece had been told the story, Robin accidentally injured

her eye while gardening (Morrison 6). “They did not have modern methods of alleviating pain” the niece recounts “and she was driven insane. She was taken to 999 Queen St., Toronto, the Ontario Hospital for the Insane” (Morrison 6). The biography indicates that she was later sent to the Asylum at Brockville, but does not indicate whether she was moved from the Ontario Hospital or from the Rockwood Asylum.

Robin’s three-year-old daughter was sent to live with relatives. It is unclear whether she was aware that her mother was alive and in an institution when the daughter attended teacher’s college in 1898 (Morrison). Robin’s family developed a narrative around her injury and subsequent illness that was added to and can be added to in the present. Many of the ill contained within the walls of Rockwood Asylum remain as checkmarks or initials in old hospital and census records. Each one has a narrative attached. Some of these have been brought to the surface in family biographies and others remain silent, signified only by inert numbers. Robin’s story represents the standard approach to insanity in early Ontario history.

3.4 Summary

The people who access services through Ontario’s psychiatric and mental health system do so from within a contemporary system of delivery of services. This system has been created over decades and was founded on early regulation and control of people considered to be mad, insane, contagious, or in some way a threat to increasingly surveilled ideas of national hygiene. In its early history, Ontario’s institutions and those vested with the power to speak for the nation on matters of health and other public concerns categorized and sorted people into institutions. This constituted a life within an institution for people considered insane or diagnosed with illnesses such as tuberculosis. Knowledge about the extent to which people resisted such

constituted identities is scarce, with Reaume's work being the most notable as it pertains to Ontario. In the interviews that follow, the focus is on first person experiences of the present system. There are differences in the extent to which people of the past and people of today are tethered to structures of correction and confinement. There are similarities in the extent of identity with over-arching static definitions of madness and mental illness.

Chapter Four: Consumers and Survivors

4.1 Introduction: Talking Madly

The lunatics are taking over the asylum. This phrase, loosely attributed to the early film industry, is meant to conjure up an image of disorganization. We are meant to take pause—something is in the wrong order. The lunatics *can't* run the asylum. But why is this so? In Ken Kesey's *One Flew Over the Cuckoo's Nest*, the lunatics do take over the asylum, however briefly. The consequence, for turning the gaze, for pointing out the dehumanizing practices of the asylum and for encouraging his fellow inmates to think for themselves is, for McMurphy, a lobotomy which leaves him utterly senseless and impotent, no longer a threat to the organization of the institution. The lunatics can't run the asylum. There is an order of practice and it stems from the locus of power which is in this case the nurses' station. McMurphy is astounded to find that many of the patients are in the hospital of their own volition. In a particularly poignant scene, he tries to take back for his fellow patients the power that has been taken from them. Through film, songs, poetry, literature and academic work madness and mental illness talk are ever-present revealing a certain and sustained fascination and interest in the subject. Mad people themselves are writing—articles, poetry, dissertations, films. It seems that the mad are indeed taking over the asylum. Beyond this, the so-called tin-hat society, it turns out, were right about so many things. Surveillance is everywhere and mind control, from the crudest experimental forms to more subtle coercions is not entirely psychotic.

Foucault discusses the subtlety and invisibility of power, which becomes veiled and employed in the modern technological project through social media and through constant messages of self-surveillance and monitoring. In extreme cases, this saturation of the mental

health message represents and results in a form of mind changing, or "power over life" (*History of Sexuality* 139), as people look to anonymous others to verify their social inclusion. Foucault articulates this power thusly:

> One of these poles—the first to be formed, it seems—centered on the body as a machine: its disciplining, the optimization of its capabilities, the extortion of its forces, the parallel increase of its usefulness and its docility, its integration into systems of efficient and economic controls, all this was ensured by the procedures of power that characterized the *disciplines:* an *anatamo-politics of the human body.* (*History of Sexuality* 139)

Foucault's theory of power includes also biopolitics, or supervision through "regulatory controls" to create a total subjugation of human beings through what he called biopower (*History of Sexuality* 139). The critical ethnographic work is situated within the context of an increasing medicalization of many forms of "abnormal" behavior. The discursive strategies of the mental health and psychiatric industry are used to influence the ways in which people interpret their own realities and experiences. By using the term "madness," activists, consumers and survivors of the psychiatric industry, resist the dominant discourse, and point, if not directly, to its insidious insertion into everyday language. Some of the participants in the thesis are in a position to engage in critical analysis and reflection of their own experiences, while others are less empowered to do so in such a way. The analysis is taken up with care to include multiple experiences, from various perspectives.

The previous chapter outlined the social historical analysis of pertinent and pivotal periods in Ontario's asylum history. Through the process of tracing Langmuir's career, as well as the substantial influence of Bryce, and Hodgetts, it has become visible that many decisions were

at least partially self-interested and economically driven and that some theories were ill-informed but were promoted nonetheless through heavily rhetorical images and threats. More important is the absence of patients' voices. Once health issues and madness became large scale social problems or species threats with large scale social solutions, these entered the realm of scientific management, specialization, medicalization, experimentation, and eventually psychiatrization. In the later period of mad history, particularly in the experiments described by Anne Collins and substantiated through the outstanding lawsuit at Oakridge, we see the privileges of the power to confine and interrogate exercised in their extremes on incarcerated bodies. It is within this context of recent and local history that the people interviewed work and access services. That the gaze has been turned back on the mental health system in favour of autonomy for the consumer/survivor does not indicate, as it is meant to, an increased power to speak on one's own behalf, as the terms and questions one asks of oneself during self-reflection are part of an a priori and extant set of things that can be asked.

This chapter hears from the people who have only recently been invited to speak on the subject of madness or, as it is termed in the questions, mental illness. These are people who have accessed services of the mental health system at some point. They have each done so for different reasons and through different channels. Not all are critical of the services they have received, and in fact many of the people interviewed have good things to say about the treatment and services they have received. The point of critical interrogation is not to compel people to take a side for or against psychiatry, nor to exploit the shared experiences in these interviews toward a particular agenda. The thesis aims to interrogate the mental illness system, from past to present and from inside and outside. In these interviews, the interview participants and I stand outside of the hospital, the clinic, the waiting room. We are aligned in our ability to see these

places from our respective pasts. All of the interviews took place away from clinics and hospitals but the questions that pertain to diagnosis sometimes take the discussion and reflection back there—to waiting rooms, bedsides, assigned lockers, nurses' stations and locked wards.

The interview participants reflect on their experiences in the present mental health system through a series of specific questions. The interviews are analyzed in critical ethnographic manner so as to present a perspective of madness that comes from the experiences of those accessing services within the current Ontario mental health system. In this way, madness and mental illness are reclaimed and described from a multiplicity of contexts in contrast to Langmuir's and Bryce's authority to speak from their political positions on matters of insanity, breeding, eugenics, immigration and deportation. A pivotal point in Ontario's history was that of the shift away from custodial and toward curative management of the insane. Although often clothed in humanitarian goals, the shift away from custodial care and toward more therapeutic treatments allowed for the next era, that of experimentation. When the patient body became the object of research, it became also the body of experimentation, monitoring, prolonged observation, and rehabilitation.

The responses to the questions are incredibly varied and reveal surprising and poignant strategies and personal reflections. Longer excerpts from the interviews provide individual sites of analyses, reflection of personal histories and critical engagement with the mental health system. The analysis is informed by and brought into conversation with the historical work that was first presented in chapter three. The extent of analysis is necessarily limited; the thesis asserts only the *beginning* of an ongoing discussion. However, it is a distinctly different *kind* of discussion. The historical discourses about madness presented speculation—opinion built from observation. Extending from this the participants of the historical discourse argued for reform,

taking and sharing their power, according to competing or mutually aimed economic and social goals, between appointed experts. These were dialogues, monologues, speeches, appeals and published letters. A wider discussion includes first person perspectives, albeit guided here by specific questions.

This is a discussion to compete with and interrogate the hygienic talk of the *Let's Talk* campaign the mental health movement, a talk disseminated by a script no less prescriptive than its psychiatric discourse. Both bodies of knowledge are directed, the latter being intentionally reflexive. The discussion here is not about getting better or accessing services, but about experiences from within the system. What is revealed in our standing outside and looking in again is how these experiences have resulted for some in a helpful diagnosis or a daunting prognosis, for others long term negotiations with many facets of the system, changes in relationships and perceptions of self after diagnosis and hospitalizations, and reflections on the nature and experiences of reality.

Cassie, for example, was the impetus for further analysis, as she so poignantly described seeing herself, I ask, how do people look at themselves, how do they look at others, and how do they think others are looking at them through the lens of diagnosis and how has this impacted on their lives? Cassie feels responsible for her illness and describes owning it as well as being aware that she is not the girl she used to be, pre-hospitalization, and that her parents miss that girl. In the process of getting relief from the discomfort of madness or mental illness, there is a negotiation between what will be revealed and what consequences can be expected. In this chapter, I also discuss the mental health system in Ontario as it is structured and experienced in the present and in relation to its history.

Other interview questions probe self-perception and identity in relation to significant others, asking if there was a point at which the interview participant began to see themselves through the lens of diagnosis, or through the lens of other people's ideas of madness? Still other questions were meant to describe in general terms the experience of being treated for madness, of seeing oneself as mad, and of interaction with the medical system and with others as defined by social roles (such as father, daughter, teacher, and artist). The rich data collected could be sorted through many more times and still yield new insights. To bring these present day experiences into conversation with the historical and, in the next chapter, the present mental health system, five themes emerged in the interview and are further analyzed here.

From the group of consumers and survivors the following themes emerged:

Living carefully under the medical gaze

Repression and relief: getting in and getting out of the mental health system

Making meaning out of diagnosis

From the group of caregivers and service providers the following themes emerged:

Cures, treatments and waiting rooms,

Spaces of madness: seeing and saying

Remembering the past

The themes emerged directly from the interviews coming out of the questions asked. The questions asked were meant to provide other possible ways of seeing madness. Specifically I asked the people in the consumer/survivor group about the process of becoming aligned with the mental health system including the period of time, diagnosis if any, and the social context of the diagnosis or mental illness. I asked these questions to probe further into the micro relations

involved in the governing entity of the mental health system, a system that, I argue increasingly entraps social aspects of humanness.

As discussed in the previous chapter, the treatment of madness has long been aligned with broader social and economic projects. The contemporary mental health consumer/ survivor have entered a new realm of governance in which she is asked to govern her own madness under the guise of autonomy. In this chapter the consumer/survivors reflect on their participation in the mental health system and the interviews are analyzed in relation to the themes that emerged directly out of these reflections.

4.2 Living Carefully Under the Medical Gaze

> My standout-ness has become just strong and woman. I just thought the people who love me miss parts of me that they don't see anymore. (Cassie)

The people in the interviews have something to offer beyond what is already known about the mental health system through mental health literature. They make visible the everyday exchanges of time, words, knowledge and experiences of the spaces and places of the mental health system. From within the mental health system they present a perspective unknown perhaps even to the psychiatrists and clinicians to whom they are talking. In reflecting and discussing these negotiations, they reveal parts of themselves they keep hidden from medical speculation, aspects of being they have rejected or kept secret, only to be reassembled in the safety of less rational domains. These aspects of being mad are seldom outright rejected—hearing voices, seeing things, chanting, performing, hiding—they are accounted for and reclaimed once the doctor's appointment or hospital stay is over. Some medications can

ameliorate some uncomfortable neurological events, but not nearly at the rate of performance claimed by the pharmaceutical industry and not without short term or long term costs such as rapid weight gain, tardive dyskinesia, memory loss, sedation and tolerance, to name a few commonly known effects.

The ethnographic perspective adds to the historical perspective and effectively sweeps a panoptical gaze across the psychiatric and mental health system. Living carefully after diagnosis or hospitalization involves a reflexive medicalized gaze; Cassie, Simon, Jane and Collin in particular describe seeing themselves, or seeing others regard their loved ones through a medical lens of a mental illness diagnosis.

I had known Cassie for many years, perhaps even ten years, before this interview. I have known her father for about fifteen years. When I first met Cassie through her dad, he was concerned about her and talked often about this concern. I had gone out socially with Cassie when she was a teenager. When I met her a few years later, she was much quieter and seemed very shy. I was aware that she had experienced what is considered to be a drug induced psychosis and that it had resulted in her being hospitalized on several occasions due to her condition. Cassie's relationship with the hospital system has been circuitous, seeing her leave to live alone in Toronto for a while, a period she laments about with nostalgia and slight self-recrimination for her youthful naiveté.

When I contacted Cassie for this interview, she was living alone in an apartment. Cassie was easy to identify with. Here was a young woman whom I had met as a girl. She was pretty and shy, self-conscious and very careful with her words. I had seen her socially many times throughout the years, sometimes bumping into her at a music festival and others times going to a movie with her. Cassie has had long term involvement with the mental health system, through

many hospitalizations and on-going community support. Cassie's experience, like the other participants' experiences, is confined and narrowed to some extent by the interview protocol; although the questions are open-ended, they cannot capture the full experience of her life, or even the full extent of her experiences from within the mental health system. Cassie speaks in wonderful images; she story boards her pre-diagnosis life, her thoughts and actions prior to her first drug induced psychotic episode and the quotidian measureable responsibilities of the present. Cassie's story begins with her reflections on her first time entering the mental health system and being given a diagnosis.

> Moira: Okay. And what was the treatment once they came to a diagnosis that they suggested?
>
> Cassie: I had been given medication in pill form. Once I was homeward; meaning to my parents/guardians.
>
> C: I didn't remain committed to my medicated option and I was also young and I had been given different options and forms of medications. I can remember being given prescriptions of medication in pill form and not seriously taking them but being in the care of my parents, independent of the hospital, and then a few years later after more hospital stays, they started being given as injections then and that's still far from where we are today.

Cassie is describing a series of negotiations—with her treatment orders, her parents, and her conceptions of herself. She sees and recognizes herself navigating through the system. She describes an awareness that she has made a contract. She follows the words I ask her carefully, answering as asked in her precise understanding of the word and beyond the word, and in its

significance for her past self, which she can see in a rear view image. She refers to a "point of sanity" which indicates something significant to her:

M: The injections, were they effective?

C: Yes they were effective. They took effect and there were side-effects I think but there's a little bit of a downfall to being medicated.

M: What is the downfall?

C: I think it changes a person in other ways. And it's a little bit of hoops to jump through in order to get to your point of sanity.

M: I was wondering if you could say a little bit about what it was like before the medication and then what it was like after the medication, when you arrived at that point of when things made sense.

C: I've been growing through the whole experience so part of it is growing up as well as changing the medication.

Cassie is able to see all her selves, and she also observes how she has changed to fit this or that process of being. Cassie is aware of the changes she has made, the things to which she has acquiesced in order to get back to an image of herself that will let her fit into the mental health system's idea of herself, and that of the self that she saw reflected in her parents' vision of her. Most poignant is that Cassie knows she has made a bargain. Perhaps she romanticizes the days she spent in Toronto. She laments that she couldn't make that image of herself work out as it was just as viable a self for her in that moment as was the medicated self she has perhaps resigned herself to. Cassie does not discuss any other experience of being "the girl in the flowered dress" than the one that she thinks pleased her parents. She has learned to live carefully, following instructions and a daily routine. She explains to me:

C: I've had an experience lately and that was whereby I'm able to have an overview look, and I'm able to understand that these people in charge of my care had an idea of what I would like and that they could perceive my illness in a way that I couldn't and but lately I'm able to feel through my treatment that I've had this outlook of myself whereby I've improved and I've overcome a part of my illness.

C: The treatment was long and hard and I'm talking hospital stays, and forms that I had partial disagreement to but abided by and eventually broke free from. I'm currently on (a medication) and it is difficult daily. It's a daily treatment so I take pills every single day and it's been a few years of this treatment.

M: It does relate to the question. I'm just wondering if there's something, you're saying that your thoughts have changed that you've grown up through this process. Is there anything else besides the medication that has been helpful in getting to the more mature perspective?

C: Yes, this is where the hospital stay was like boot camp in a way so I learned some hospital stays where we'd get up at about 8:00 and we'd have our breakfast pronto, we'd make our beds and…

M: Routine?

C: Routine and structure and I think that's having an effect, I follow that and abide by it today.

Near the end of the interview, Cassie discusses how she feels others see her as she "witnesses family," both with her in it and with her standing outside of this significant part of her life. At this point, she became quite tearful and in the separated quotes below, she describes the cost of straying from her careful routine. She knows she can go back at any time to the less careful life

but she sees the risks now. Reflected also in Cassie's story is self-admonishment that she chose to take risks with herself.

> Cassie: Uh-huh, yeah, I say yeah because what I was trying to say is that somehow I'm still able to witness family. And I think the deep sadness came from not having family. I can't even begin to describe the wretch that I have imposed within my family. I don't know that parts of me that they remember will ever return in the same way that I was.
>
> M: You mean the other parts, you mean when you were a little girl?
>
> C: My connection to that is just there's almost a, when I was young, like early 20s and doing my time at the hospital I had a journal and I haven't looked at them in a while, but I know just from those memories they are very, and this is where Moira's comment, that I had a bit of a grasp on what was crazy, it showed through with my art and my poetry.

At this point Cassie described her pre-hospital, pre-diagnosis self, when she spent time living in Toronto. It was the late nineties and Cassie wore green Doc Marten boots and flowered dresses reflective of the fashion. The tension of knowing those boots, that life, were preserved only a few feet away in the closet was remarkable to Cassie and to me. She took out the boots, ran her fingers over them, and put them back. Finally she described what they meant to her.

> Cassie: This is the last chapter. I had worn boots all the way through post-puberty, and this is the last pair I wore. These, I bought in Toronto, a city that I spent some time in as a young woman.
>
> M: You said that for them, parts of you will never return? What did you mean by that?
>
> C: Well, just the growth from being the girl who wears green flower dresses to a young woman who's very strong and very fortunate.

M: What about the green flowered dresses, when did you wear those? Or what significance does the dress have?

C: I was just describing myself cause it was still o.k. for me to be me, and just because I make my bed these days doesn't mean I shouldn't put my boots on once in a while…I guess what I meant by that is I used to stand out in ways that I don't these days. My standout-ness has become just strong and woman. I just thought the people who love me miss parts of me but they don't see any more.

M: The parts being where you stood out and it was O.K. to stand out?

C: I guess when I owned my illness.

M: Do you own it now?

C: Um.Yes. It's all mine.

Cassie's insights—her awareness of what she was doing in Toronto, her awareness of how carefully she must live now— and the tensions between stability and change in particular have to be carefully negotiated. A particularly poignant feature of Cassie's story was her description of herself as once having been someone to her family that she no longer is. Stability indicates progress for Cassie. It is as if the adherence to habit and regimen has become the measure of functionality and independence. The tensions for Cassie also include those between autonomy and guardianship, between being carefree and spontaneous and being careful and following a plan, and between being compliant and being defiant. Under her father's legal guardianship, she is resigned to regimented living and she acknowledges signs of recovery in her daily living.

Her relationship with what is called mental illness involves a set of negotiations, the first indication of which she pinpoints for herself (and as a change in her relationship with her diagnosis), is being given a medication in the form of an injection. She associates this with her

not remaining committed to her "medicated option," a choice she made and one for which there is consequence. Cassie also outlines the structure of her care at this time, wherein she was in the care of her parents but independent of the hospital. In Cassie's case, her illness, the diagnosis, treatment, and history are attached to a formal system of the hospital. The hospital is where she learned the importance of routine—a measured, visible set of tasks, like making her bed, that indicated at least the possibility of participating in further expectations of the day.

Simon has been a good friend of mine for a number of years. We met through mutual friends and had a lot in common. Simon agreed to participate because he was interested in the subject and he certainly had a lot to offer from his perspective of someone who had a long term, carefully negotiated relationship with the mental health system. Simon has also learned to live carefully, to reveal some things and to keep hidden other things. He described a strategy of keeping hidden that which he perceives will be rejected; if word gets out, he will be rejected from normal social interactions.

> Simon: Well word gets out. Your family and friends who do find out, they tell other people, and what happens is you do become socially isolated because people think "geez buddy's got a mental illness there and he could snap…there could be a bad scene or we might have to share the burden of something untoward or illogical, even devious, in our social milieu. So you do become socially isolated because people are afraid. (Simon)

Simon is careful to conceal things from psychiatrists as well, as he is aware that some aspects of thought processes are considered cause for alarm. He describes his initial confrontation with the diagnosis and explains that he immediately recognized that it had implications for his future and for how he would be perceived through this diagnosis. The diagnosed self stands outside of the hospital system, but is captured by its lingering gaze of authority. In the following poignant

quote, Simon describes the visceral experience of being diagnosed as having a form of schizophrenia. Although he recognizes or believes that some thought patterns, if left unchallenged, can lead to delusional thinking, he also recognizes that there is often reason to keep thoughts and beliefs hidden.

> Simon: Well it was a disconcerting diagnosis because as she explained it to me I had a delusion of reference I was incorporating events around me into a central play that was psychotic. So I didn't like it. I tried the medication for a while and I don't, know it made me stupid and dumbed me down which I guess is the idea of the anti-psychotic to get rid of those higher end thoughts
>
> M: Okay and so do you have any idea about what that word meant to other people? How did your family react?
>
> S: No, they didn't know. I was single at the time and I didn't really tell anybody I didn't like the word schizo—sounds like psycho
>
> M: Tell me a bit more about that, those words. I guess that's what I'm trying to get at where these words come from and what they mean to us
>
> S: Well for a person with a mental illness diagnosis anything with the SKZ in it—sound—is offensive like schizophrenic or schizoaffective
>
> M: Why is that?
>
> S: It because they're hard it's like an axe. An axe has been blunted into your personality that says you got an skz. It's not a happy diagnosis. But the bi-polar as opposed to the manic- depressive that's a nice soft diagnosis. It's not offensive.

Later in the interview, the importance and relevance of terms came up again. I asked Simon again about the meaning of words and his response makes apparent a personal negotiation that is made when a diagnosis is given and taken in. He describes it as the wearing of a badge that he can see and others can see. Beyond the stigma that attaches to people in many facets of social organization, Simon is making visible all of the authority beyond the office or emergency room where he first heard the SKZ that would shatter his personality and keep him socially isolated. Beyond the stigma that he will wear as a badge, Simon is asking if it could be broken to him more gently, more softly—Simon is interrupting the psychiatric discourse to ask for a moment of pause and reflection and to allow a moment for him to describe himself.

Jane was another person for whom entry into the mental health system and making sense of a diagnosis involved living carefully through the lens of that diagnosis. This is not to say that diagnoses in themselves are harmful; indeed, many people found a mental health diagnosis helpful as well as daunting. The degree to which the experience was helpful or one of apprehension depended on several factors, including what the diagnosis was, the degree to which mental illness or madness had impacted life prior to receiving a diagnosis and the degree to which the diagnosis had facilitated access to support services. In the next excerpts, Jane, Holly and Collin discuss hearing the diagnosis and what it meant for them. Where Simon has described his diagnosis of schizophrenia as being like an axe blunted through his personality, Jane, Holly, and Collin describe diagnosis as a double edged sword, with costs and benefits. Having a diagnosis for some means entry into a world of supports, explanations and understandings.

Jane's relationship with the mental health system came about after years of trying to get relief on her own. She describes her illness through the lens of her own expectations of herself, as she feels disappointment and failure in her role as a mother. Her sense of madness has been

coloured by the depictions of dangerous manic-depressives seen on crime shows. At the time of the interview, Jane was living with her two teenage daughters, both of whom were preparing to leave the home and attend university. Jane discusses her coming out as having a mental illness diagnosis as being similar to the process of coming out as gay. Jane discusses the difficulties of not knowing when she is expecting too much of herself and when she is just having the same feelings as anyone else (who do not have a diagnosis). She discusses the reactions of people when they found out that her time off work was due to "mental health issues." Jane describes the strategies she employed in her attempt to fit back into her workplace and her experience of the reactions of others, which included evasiveness and avoidance. Jane has also been affected by the perceptions of family and even of her psychiatrist, who first asks her if she really wants to get better:

> Jane: Yeah, and, I can't actually remember, what, and I guess it's just that I walked through recovery. I guess, y'know, you learn things about yourself and, y'know, I had to take a look at my sexuality first and, fine, dealt with that and, y'know, you just peel off the layers. And I was talking with my brothers about, y'know, and I guess I've known in the back of my mind for a long time, just that my emotions were REALLY big compared to other people. And that, y'know, ten, twelve, thirteen, years and I was still struggling to just kind of cope on a daily basis with all my emotions. And I talked with people and was doing everything else that I should be doing. I can't remember the something that precipitated it, I was in a relationship that was failing, whatever. So I went and I was diagnosed with, he said borderline personality disorder, and at one point in time he showed me the assessment, and it said "borderline/bipolar." I've read information on both, I don't really identify with bipolar, and I identify a lot with the borderline, so…

M: Okay.

J: Yeah.

M: Okay, so what did they suggest, medication or treatment or…?

J: Yeah, he suggested both. He's a really cool psychiatrist.

J: But um, anyway, 'cause the first question he asked was, "Okay, so what do you want? Like, what do you want from me? To get better or do you just want to get on disability?"

M: Yeah.

J: And it was so, I almost started laughing, but I said "Are you joking?", and he said "No." He said that there's a lot of people that come in here that just wanna get on disability, and he wasn't being rude.

M: Yeah, yeah.

J: He was just saying, "I need to know what you want"

M: Yeah, yeah.

Jane continues to discuss other areas of her life where she had to tread carefully, aware that people saw her differently after entry into the mental health system. She faced misconceptions about her mental health not just in the first visit with the psychiatrist, but also in encounters with her coworkers and her recovery support group. Here she describes one of her experiences in returning to work.

Jane: Yeah, I took sick leave at work, eh? And, yeah, they were very nice people, they're good people, y'know, but you could tell they had a certain perception about mental illness, y'know? And I tried to say as little as possible, y'know, and as soon as you don't say anything, they read into it, eh? Yeah, so they put on my assessment slip. I'm trying to remember what they put, I don't know if they put mental illness or, anyway, they put

something that surprised me, ‘cause normally if you didn’t have anything but a doctor’s slip that said, “she was off work,” you know? You would put “sick leave,” or, and yeah, I was surprised at what they put. So I could tell by the way it was handled, that despite the fact they were beautiful people, they had a certain perception of mental illness that, yeah, really didn’t feel very good, on my end of it, you know?

M: Can you say any more about that stigma? I guess because it’s *their* perception and not yours.

J: Well I had to go into the office a couple of times and just the looks, the people that I had gotten along with so well, instead of “Hey, how’re you doing?” ‘Cause if that was me in reverse, knowing what I know today, it would be, “Oh, it’s so good to see you, how’re you doing?” It’s like, nobody said anything, it’s hush, hush, that you could feel the tension, y’know, it was just…and I was like, “Hi!, How’re doing?” and I was trying despite the fact that I was a little bit nervous, I was trying to and they, they would say “hello” and stuff but nothing but nothing more, like, y’know. And so I just gave them my slip and y’know I left and I didn’t even check once and so. Because I was watching *Criminal Minds*, that’s just one of the shows I watch, *Criminal Minds*, it’s about serial killers. Well they do these, what are they called? Profiling. So they do a profile, well one of them was, and one of them had borderline personality disorders, this is what that means, and looked at my daughter and we both burst out laughing. But it’s on public television, prime time, on personality disorders, but someone sitting on the couch who didn’t know that, if they heard, “Oh, he’s got a borderline personality disorder!” they’d assume I’m running around with a fuckin’ butcher knife, y’know?

Holly is another person for whom the diagnostic process brought with it a change in her perception of herself and some thoughts about her future. We met several years ago through mutual acquaintances and occasionally went for walks or to a movie. From time to time, Holly has needed to access emergency care through the hospital system and she is quite involved with community support services. Over the years, Holly has come in and then gone out of my life. She struggles, more than some of the other people in the interviews, with perceptions of herself and with social relationships. Here, Holly describes the diagnostic process as helpful, but also describes what she was thinking and feeling prior to accessing help and afterwards. This excerpt is necessarily long to capture Holly's experience in coming to terms with the diagnosis.

Holly: So it would be 2001.

M: Okay, and ah, that's the period of time. And what happened then? What was your first entry into the system, so to speak?

H: I had a manic episode. Yeah. It was drug-induced.

M: And do you, can you talk a bit about that, what the experience was like?

H: It was really scary. Yeah, I was very frightened. I didn't understand what happened, what had happened to me.

M: Yeah.

H: Yeah. And I didn't seek out professional help for a good year or two.

M: Okay, and so, it was scary and you said you initially didn't access help?

H: Right.

M: But you had the, the manic episode. Where did you go from there? Did you wind up in the hospital?

H: Not, not for a good year or so.

M: Oh, so you had it by yourself?

H: I had dealt with it and ah, yeah, I just, I didn't believe there was anything wrong with me, I thought it was everybody else.

M: Okay. So can you talk a bit about how it felt?

H: I didn't, it felt like I wasn't in control of my own behaviour. Yeah, yeah.

M: Okay. What kind of stuff were you doing or…

H: Well, at one point I was considering taking my ex's life.

M: Oh.

H: Because he was abusive and ah, yeah.

M: And how did that idea get out of your head? I'm really glad it did because we, we wouldn't be having this conversation.

H: Yeah, exactly. Just, the urge passed very quickly. It was something that I did. I even went as far as going to my bank to, to, get the money. I was going to go to Toronto, get the gun and then I ah, the bank was closed that day and by the next day I was onto some other psychosis of some sort.

M: Okay. So you're terming these, you hadn't sought professional help at this point but you're using the words manic and psychosis. Is it looking back at it that you see that that's what it was?

H: Yeah, looking back. I didn't know at the time what it was. I didn't know.

M: Okay, so what was the psychosis then like?

H: Oh, voices.

M: At this period of time?

H: It's really difficult to describe. You know, it's, I heard voices, I would act on the voices because I believed the voices, that that was my reality. So if a voice told me to do something, I would do it.

M: Okay. And just, I am going to apologize for probing so much here but it's quite important. Can you remember what kind of thing the voice would say?

H: One was to kill my ex, for example. I had a huge fear, phobic that I was going to jump off a bridge and take my own life, out of control, even when I didn't want to, even when I didn't want to.

M: Okay, so at some point you did access some help?

H: I did. Actually, my mother actually, she accessed the help for me so the first time I went to a psychiatrist I got put on anti-psychotic, 10 milligrams of something and that began to work fairly well for me. When it stopped working there was this whole series of, for years, in and out of psych wards, medication adjustments and I wasn't even my own advocate. I was just in the system and they had control over the choices that I made.

M: How so?

H: I had no say in my own treatment.

M: Okay. Were you hospitalized for part of that time?

H: About twenty-five times.

M: Oh. Like, on a form?

H: On a form. Usually on a form or self, yeah.

M: Were you aware of what authority they had to, to…

H: No.

M: Okay, so was there finally a diagnosis given?

H: Yeah, they had diagnosed me with schizophrenia and depression, yeah.

M: Okay, and what did that mean to you, when you, do you remember when you first heard that word?

H: It ah, I was in denial, yeah. I didn't, I didn't want to believe it. My uncle had schizophrenia and it scared the bejesus out of me because he, he did jump off a bridge and was a paraplegic in a wheelchair and, had several suicide attempts and I just didn't want to accept that I had this same disease and today the diagnosis has been changed.

M: And what is it now?

H: It's a dual disorder which is bi-polar and schizophrenia.

M: Okay, and does that term mean anything to you?

H: I have a much, much, much better understanding of my illness today so it means a lot to me, yeah.

M: Initially, when the diagnosis was schizophrenia and depression, what was the treatment?

H: Well, again, I had been on several other medications. I'm sorry but I cannot recall all of them.

M: That's okay.

4.3 Repression and Relief: Getting In and Getting Out of the Mental Health System

And I said, "Doctor, I like you, but I don't think you understand the creative psyche," and I said "I'm an artist." (Christopher)

[*A]ll available help was presented just short of actual help…there was no help.* (Simon)

Getting help for the symptoms of what is called mental illness necessarily involves presenting oneself for diagnosis. This process happens voluntarily or, through an involuntary formal committal process. This is called "being formed" or "on a form one" in reference to a specified involuntary hold order, during which time the patient is detained and held as dangerous to him or herself or others. There are many terms specific to mental health insider culture that are specific to the hospital experience, but more broadly, mainstream culture claims a wider berth in its descriptions of madness. Going crazy, being crazy, losing it, going off the rails indicate a departure of sorts from some place or state. Mental health talk threatens to displace mad talk by presenting instead medically sanctioned, rational descriptors for these metaphors. They aim to reason unreason, once again. This represents nothing short of a loss for those inside and outside of the experiences of mental illness and madness, as mental health literature and mental health campaigns threaten to corral and manage all experiences of thought and mind.

Mad people have been talking madly before asylums were built and continue to talk madly beyond the walls of asylums. Reducing madness to an event placed vaguely within the past and present of the mad person's body, as asylums and early alienists did, proved to be an effective strategy; it authorized asylum officials to speak about madness from above the body—from outside of it. Over time, alienists, psychiatrists, psychologists and more recently, mental health specialists of a wide description claim authority to talk about madness, reframed as mental illness and mental health in a nod against the stigmatizing effects of madness. That madness' moment of modernity in the late nineteenth and early twentieth centuries had lingered too long over a quieted mad body, or a raging dangerous one, was ostensibly ameliorated in the talk therapy models of the later twentieth century. Talking is one thing people who are accessing mental health services are now asked to do over and over again. In these interviews some people

describe the place of talk in negotiating relationships inside of and outside of the mental health system. It is important to note here that while the mental health movement essentially cleans up its language for wider consumption (all help is available, just not now), stigma goes far beyond the control of what a particular word gestures toward; diagnosis gets under the skin to a silent place that is protected, sometimes, from the next blow, prognosis, which is as Simon says, "like an axe blunted through your personality" (Simon).

Most of the people who participated in the interviews have exceptional use of language and imagery, a feature, no doubt, of our mutual attraction. Descriptions of the experiences of terror, joy, fear, humour, boredom, anger, nostalgia and other experiences made significant contributions to my understanding of experiences from within the system and experiences of coming to terms with a daunting diagnosis and prognosis. The questions for the group categorized as mental health consumers and/or survivors were meant to make visible the ways in which relationships with oneself and with others are organized from within the context of a mental health diagnosis. Entry into the system involves a series of negotiations for people diagnosed and sometimes for their families as well. After and beyond diagnosis or hospitalization, there is another set of negotiations, a second layer. The next sets of negotiations tends to come after someone has had an initial diagnosis and after some time has passed, sometimes letting the diagnosis sink in, other times rejecting it in whole or in part. Cassie and Simon live carefully, Cassie monitoring and tracking her wellness according to daily functions, and Simon profoundly aware that something fundamental in his person has been attacked.

Some people described a process of seeking relief or repression when needed but otherwise, as in the case of Simon, devising strategies to avoid involvement, especially when it may include confinement. Others, like Quinn, seek repression of uncomfortable feelings but

describe their experiences in their own terms. Similarly, Christopher describes matter-of-factly his own interpretation of his madness. He is willing to draw from psychiatric literature such as the DSM, but again, in his own interpretation, particularly of his misunderstood sexuality. Christopher, Quinn, Simon and Brent have each spent time in hospitals, receiving care for what has been diagnosed in almost each case as a mental illness. Each has had a different experience and relationship in negotiating mental illness or madness. Sometimes this has involved seeking relief in the form of sedation, as Simon and Quinn discussed. Christopher accessed the hospital system first in a crisis and then he found that one doctor listened to him when others in the community had violently rejected him. Brent represses, through self-monitoring the limits of his creative thoughts and ideas in exchange for a safer range of emotions. Christopher's, Simon's Quinn's and Cassie's stories in particular could be well told in complete narrative form. Each of these stories, through selected excerpts, serves the purpose of providing personal experiences of the phenomenon of repressing aspects of post diagnosis selves and seeking relief when the pain or pressure of being is too much to bear.

Christopher is well known in the community. On some days, as when he is dressed as Stravinsky's "Firebird," he welcomes the attention, but at other times, he dismisses the looks he receives as examples of small town rudeness. Christopher has experienced many years of being singled out, bullied and ostracized. He describes his first entry into the mental health system, after years of being physically and verbally assaulted. He describes also his negotiating his own right to self-describe as well as the meaningfulness of the relationship established with one doctor in particular. The doctor's version of Christopher, a man out of time, was sympatico with Christopher's own self-perception; it wasn't Christopher who was out of step, but time and place. Essentially, the doctor provided cognitive resonance for Christopher's theory of being.

Christopher is wordy, addressing almost every question with references to literature, medicine or personal anecdotes and reflections. The excerpts are necessarily extensive in order to access the range of his reasoning and making sense out of his painful experiences. As well, Christopher makes visible a rather unique critical perspective of the use and limits of language, effectively inverting the power of diagnostic language.

> Christopher: Yes. I was seeing a psychologist, psychiatrist. The doctor who was about the only qualified man in all of Northern Ontario who understands Marfan's and my problems were compounded by ignorance and xenophobia, homophobia, and just ignorance. I was constantly being assaulted and all my life it's been like this and at times it would get so overwhelming I'd get very, very despondent, depressed and I'd have nervous breakdowns. So when those occurred I'd be hospitalized, I'd get over it and then I was fine. And that lasted from, I met him in a suicidal bout, where I took an overdose in 1984 at hospital and he talked to me talk about poetry and he was British, studied at the university in medicine and forensic psychiatry and all that and because his father was a painter, and an artistic painter not a house painter, he understood the creative mind.
>
> C: He remained my doctor till he had a double series of strokes in 2004, so for 20 years he was my doctor and he'd tell me constantly, he says "You know, Christopher if you were a rock star, if you were like Elton John, David Bowie, you'd make it, but because you're a poet and because it's Sudbury, they don't comprehend," and I kind of told him the same thing myself. He would listen to me and he says, "You know people who don't know you probably think you're psychotic, right," and he says "You're problem," and I said, "My problem is I was born either a century and a half behind my time, or I'm born

> 30 years ahead of my time." Like I don't fit in you know? And so he understood that and said, "Christopher, you're too lucid to be psychotic."

Christopher's doctor concurs with other explanations for Christopher's social experiences and as well provides a diagnosis completely outside of the mental illness or madness diagnoses. Christopher, he explains, has Marfan's syndrome. This diagnosis enables Christopher to continue and indeed to build a therapeutic relationship with the doctor while rejecting the stigma of madness. The wholeness with which the doctor had approached Christopher's case perhaps facilitated the self-acceptance which was apparently a feature of Christopher's post diagnosed self. He continued to engage with society as an exceptional poet—recognizable, familiar, still often harassed, but with credited explanations for this annoying ignorance. Christopher explains his exceptional internal experiences in mystical terms. In this excerpt, Christopher describes at length and in detail his first experiences with being hospitalized, what led to his often short lived hospitalizations, and his perceptions of his experiences.

> M: So what was the period of time then that you were receiving…was there anybody else you were seeing?
>
> Christopher: The first time I started seeing psychologists was in 1977, I was at (university) doing my BA in French and Religious Studies. I used to get attacked even on campus, physically attacked.
>
> M: Literally attacked.
>
> C: Literally assaulted, assaulted. And at some point, summer May 1977, I was 22 going on, I was on the verge of, I was 22 going on 23, because my birthday's in December, and I was tired of this because my whole life had been this, and I had had a nervous breakdown, and I had, yes, originally, yes and I was put on sleeping pills because I was

kind of overstressed and I couldn't sleep, I had insomnia. And I took the whole vial, passed out in the student lounge at the (university) and just before I took it I had a mystical vision. I experienced the mystical vision of experience by St. John of the Cross. What he wrote about, which I had read and I was familiar with mystical writings, I was doing a degree in Religious Studies like a double major, but I never would have thought I would have actually lived this overwhelming cosmic void that I was this inconsequential human grain of pollen in the universe. And it came on so suddenly on top of a very difficult summer I was having socially at home and socially also. And it wasn't terrifying but it was anguishing, trying to see and I've lived it and I saw, it was like my mind went across the Milky Way galaxy and I could see it as visually as I see you, I had a literal vision.

There, and then, "Well, Christopher do you believe in the Lord as you do inside of me, at a very deep level?" And I was already in a prayerful state because I sat down first of all, I started crying, I was all by myself, and I was praying to the Lord to help me overcome this mood kind of thing and then this vision came on and said, "Christopher you're spirit, you're living the mad of experience, the great nothing *no thing* of awareness." And at the end of it, it was like I've experienced an omnipotent, omniscient—I'm going to invent a term, an omni-directional existence of the Lord in the whole universe. I became one with the universe. I became one with the Christ-consciousness. I lived the omega and the alpha, a mad experience one after the other, at some point they fused and I was trying to, and I was questioning the Lord inside of my soul, I'm saying, "Lord Jesus," inside my head, my soul, "How am I going to convey this or survive this?" Because it transformed me and at the time there was no social indication

of any help for me to transcend, like the total incomprehension I was living, and I downed the vial of sleeping pills, asking the Lord to forgive me and then I passed out.

I was unconscious and they found me in this state and they brought me to the hospital and I recovered there. And in the hospital, because I'm dealing with some behaviorist type psychologist, they're atheistic or agnostic, they don't even believe there is a God, or there is a higher power, whatever, I would not discuss this experience, and I knew it was a mystically deep thing they could not understand so I kept it to myself. I started writing about it in French and when I came out, and of course well after I was well enough physically recovered, I'd go to group therapy things.

At some point there was this guy who was the facilitator of the group, this guy (anonymous), and I started talking about the history of psychoanalysis from Freud on, and I said, "Well, I disagree with Freud however I do agree with one thing he said, 'I sublimate my id ". Then I'm talking about psycho-synthesis by this Italian writer called Roberto Asagiolli, who wrote a book called *Psycho-synthesis*, which I have read, and the facilitator—I didn't realize I was going to monopolize the whole group that day—but everybody listened to me and it was like people were absolutely amazed.

M: I'm hearing that you're saying that it was a metaphysical experience because people wouldn't understand that so did they try to attach a diagnosis?

C: Well at the time, because I was starting to become flamboyant, they thought I was manic-depressive and I had read about psychosis and I knew I would look manic-depressed, and I said, "No, I think you're confounding vocabulary. I am not bi-polar." Well those days they said manic-depressive, which became bi-polar later. I said, "No, I don't have these extreme swings of moods. I am just depressed because of societal

factors." "Choose your vocabulary," I'd say to this female doctor who was treating me then, and her own son committed suicide so there we go. And I said, doctor, I like you, but I don't think you understand the creative psyche and I said I'm an artist, I'm a writer. And, you know, because I wasn't published yet, and it was like Sudbury in 1977, and I was starting to dress a little bit like David Bowie and Mick Jagger, you know doing their thing, here in Sudbury 32 years, you can imagine the public and people would ask me why, and I'd say, "Well if they can do it, why can't I?" I don't care about Sudbury miner fashion. To me, it's o.k. for them, but it's not me. They're stereotypes from people who, many, they come from mining families. They may be educated in maybe nursing and a lot of them haven't travelled, they're not cosmopolitan. They don't read much. They don't understand the creative artist at all. And somebody dares to defy the stereotypical macho norm which is what is popular and the general persona here because it's a mining town. Well then you're either back way even if you're not, and you're immediately put in a stereotype and of course well all gays are feminine right, and it's not necessarily the case. I've met some body builder types who are very, very homosexual or gay or whatever. But this mind set. That's what I'm saying.

And because I'm very, it's ironic, there's this famous homosexual whose name was Quentin Crisp, he did a film called *The Naked Civil Servant* and he was very feminine, very, sometimes even a drag queen. And I was born on the same day as him, December 11, and I tend to be very exuberant and outrageous at times, but there is always a point, like once I show you that article in the paper, I'm dressed like the firebird, the photograph was taken at a table outside of here. And I said, "I am the Firebird by Igor Stravinsky, very famous Russian composer who wrote a ballet." Well this is what I'm all

about. And I knew that day I was going to be interviewed so I deliberately dressed up. I thought, well I knew, they were going to photograph me, they'd told me so, so I said "I'm going to make history in my way. I'm going to dress in an outfit like nobody else would have the imagination or the daring to do".

M: Was there ever any diagnosis that you felt, "Oh, okay, that might make sense?"

C: No. I knew they didn't understand. In the subsequent times I was hospitalized for nervous breakdowns they would always change their diagnosis, which told me that I didn't fit into this preconceived psychological group. So at some point I said, "I do not want to take this medication anymore because it just makes me like a vegetable, and it is not what I am, and the psycho-diagnostic is wrong." I'd tell them right to their face in that language. And then I'd go into the Diagnostic Manual of Illnesses and have read it, and they're dealing with someone who knows as much about their field as they did. And lots of them were a little bit turned off or would not admit they were, kind of, they felt, and of course some people…one doctor said I was a transvestite. I said, "Excuse me, but transvestism does not appeal to me. And most transvestites are heterosexual," and I said, ah, "sometimes I'll wear the odd female article but not from head to toe. And I do not wear female undergarments, so if you're going to call me a transvestite you'd better know what you're talking about." And then I went into the *Psychopathia Sexualis* by Krafft-Ebing, and I said I've read this, and I've read *Masochism* [*in Modern Man*] by Theodor Reik. They were just absolutely overwhelmed.

Quinn also describes her experiences from outside of a medical, psychiatric diagnosis. For Quinn, lots of people have some post traumatic event that they are trying to live with. She assumes in our interview that I have an unnamed "post traumatic". I don't dissuade her from this

notion but not in a disingenuous attempt at camaraderie—I had just not considered this as a general explanation for present experiences of past painful, traumatic events. At the time of the interview, Quinn was waiting for a bed at the local psychiatric facility. Quinn describes also the process of getting relief beyond the process of getting a bed and some rest. Quinn has resisted formal diagnosis but not in defiance of the system; she sees diagnosis as inaccurate, both in her case and in that of others. She describes helping people to navigate through the mental health system, having firsthand experience with the buildings, the processes and the characters within. Her language is descriptive and accessible, though esoteric at times, requiring a decoding which she is willing, almost dutifully so, to provide.

Post-traumatics and milestones mark the pains of her life. She references Jimmy Hendrix and the Jehovah Witnesses, she has kept a vigil from her own watchtower, which at one time was the top floor of the local psychiatric facility, and, at another, the hidden alcove of a local community arts organization. From inside and outside of the mental health system, Quinn bears witness, through the inscriptions on her own body, which has been violated (and then this violation dismissed). In this excerpt from Quinn's interview, she describes seeking relief from the psychiatric hospital system; on the day of our visit, this relief will come in the form of a bed and some rest. It is a hot summer day and we agree to meet in a restaurant in Quinn's neighbourhood. I am familiar with the place and with Quinn, having had many conversations with her over years of living in the same community. Quinn, like Christopher is well enough known in the community—if there is such a thing as mad cred, they both have it. On this hot day, Quinn is waiting for a call saying there is a bed for her. She is tearful, but insists that the interview will not be any more stressful than the waiting. The mental health system offers itself as the only form of relief from acute or chronic experiences of what is called mental illness and

madness and Quinn feels that she has become a burden on her roommate and requires more care than he can provide. Quinn relies on the mental health and hospital system, she does not entirely trust it. Getting in to the hospital system and all the supports and explanations it offers has been for Quinn, a series of negotiating and making sense of explanations or diagnoses of her experiences that don't quite fit her own narrative explanations. As well, Quinn considers herself particularly adept and skilled in knowing what people are after and what they are hiding.

> M: We can begin with just, your first time, when you first tried to get help through the mental health system.
>
> Quinn: Dr. S. who passed away of Lou Gehrig's disease. He was my admitting doctor and I told him in no uncertain terms, "You are NOT my doctor, you know the truth". He brought, his son brought his records to Austria, and that's where his ashes were laid.
>
> M: O.K.
>
> Q: So I can't get a hold of, I am trying to get a hold of my records, but he got me a new doctor and his name is Dr. T. Now there was two dynasties. The first one and the second one. I don't know if you are into the dynasty end but look into it.
>
> M: Mmm hmm…
>
> Q: Anyway, he wasn't a psychiatrist at all. He was a farce.

The necessity of disclosing these details about Dr. S's death and subsequent death ritual, in which Dr. S's records, not his body, are taken and burned, are not revealed. They clearly have meaning for Quinn as do the other details that she reveals, sometimes cryptically and at other times directly, and they offer an explanation for Quinn as to why she is unable to get a hold of her records. In this excerpt, understood in the context of the entire interview, Quinn is claiming sovereignty of her own insights; if she could just see her records, she could certainly decipher

them more accurately as she is in the unique position to comprehend the relevance of the "post-traumatics" (in her case, incest and the resulting stress). What is central to this piece also is that Quinn states emphatically, "You are NOT my doctor, you know the truth," the truth being here that Dr. S does not play the role of doctor in Quinn's perspective. Instead, it is that they both play the respective roles assigned to them by the mental health system in order for each of them to get what they respectively need.

Quinn has a particularly keen perspective on the process of getting into and out of the system. Having difficulty getting help to deal with "milestones" or hardships, such as sexual abuse and the loss of several loved friends, she self-describes as having "post-traumatic." She uses the term, not in a clinical way, but as indicative of an actual milestone or touch stone in her life, a place in time and space that, when she goes back to it, she finds sadness and pain. Quinn' "post-traumatics" are plural and historical and she claims them in a way she never seems to have done with other diagnoses, which she describes as not having meaning. In this excerpt she describes her milestones and there is a subtle speculation made that the "mental illnesses" she has experienced (and that she has witnessed in others) are actually "post-traumatics." It is revealing that she only uses the clinical term "post-traumatic stress disorder" once and that she continues to describe the experience in terms of events such as unpleasant things that have happened to herself and others; some of these being violations of the physical body, to which she alludes without great detail.

There is in her recounting a startling juxtaposition of perspectives: that of the medical lexicon and that of Quinn's self-diagnosis. The diagnoses offered to her by the mental health system are primarily those involving illness of the mind while she perceives that the symptoms

of stress and anorexia are physical symptoms of a physical injury, these being sexual abuse and overwork.

Q: I was never diagnosed with post-traumatic stress disorder and I should have been by Dr. C. I told about the incest and he said that's your families' business and I said O.K. He said go home and tell your mother. So I tracked my mother down at my sister's while she was in the hospital getting ready to have her second child and, with Joansie witnessing, and she slapped me across the face and called me a liar. And that set me back. That was another milestone that set me back. Real big time. By Dr. C and my mother.

M: So these milestones are more indicative, the milestones seem to be more meaningful than any term, any diagnosis? Is that correct, or…

Q: The milestones is the post-traumatic over and over and over again.

I wasn't diagnosed. I had Dr. C as a doctor. And I told him what the situation was. I had to. I had to finally let it out about the incest. It was interfering with my work. I was becoming an alcoholic. My grandmother had died (she gets emotional here) and I beat up my husband and I had a lot of guilt on me. And, yes, men do get abused by their women and I told that to a social worker in Sault Ste. Marie and uh...anyways...a lot of trauma back then: A lot of things happening at once?

Q: (continued) So I said, I got to get back to up north. Toronto is not my cup of tea.

[…]Q: I don't know who diagnosed me with bi-polar to tell you the truth.

M: Does the word, does it mean anything?

Q: Manic-depressive for Jimmy Hendrix was (laughter) helpful, but for "All Along the Watchtower" and the Jehovah witness and it depends on the arching of Edison's light bulb.

M: How so?

Q: The arching?

M: Yeah.

Q: Between the left and the right hand.

M: Mmm hmm.

Q: It depends where it starts arching. Does it start arching from the left or does it start arching from the right. How would they know?

M: [little giggle] okay

Q: You'd have to be a brain surgeon to know that.

M: Yeah. O.K., so, if I understand you it's not an accurate diagnosis because they can't really tell?

Q: No they can't. They can't tell at all.

M: Would you prefer to just not have any manic-depressive, bi-polar, any term?

Q: Exactly. It's post-traumatic. Lots of it. Lots of it. I've lost a lot of friends [emotional here]…and I've got no place, no time to even mourn them. Oh, they've also got me diagnosed as schizo-affective disorder.

There is a taken-for-grantedness about the medical treatment of madness for Quinn. Outside of the mental health system, which she will access as she needs to, Quinn sees her role as that of an advocate. She has cultivated a social network that does work for her and one she has to protect. Quinn describes needing relief, for herself and those around her, from a non-mental illness perspective. In some ways, perhaps Quinn has made a negotiated agreement that, although her symptoms (which, interestingly, she does not describe) can be attributed to injuries and states of the body, her only chance to get "some peace" is through the psychiatric system.

In Quinn's story, she is a kind of soldier, and her battleground is the streets where she lived for an undefined period of time. Quinn has fought to be heard in the mental health system and she describes being comfortable outside and away from the mental health system. Well-read and well informed, Quinn has taken it upon herself to share this information with others if it will be helpful to them. She is aware that many people do not have the knowledge that she has and she is kind and patient in explaining things to me, and from what I learn in her story, to others in her past. Quinn has come into the mental health system almost accidentally; she has largely been misunderstood, not heard, and not believed by authority and protective figures in her life. In some ways, Quinn is a veteran of the system. Her description of her time in the system can be read as an inscription. Quinn makes meaning out of voices that no one else hears, sees things, and has points of reference that create what could otherwise be a terrifying and lonely existence.

Quinn talks about her time on the street as a choice and she describes, in a dutiful sense, her role as protector and vigilante of injustices and debts owed. But Quinn does not tell the story of her long vigil with vengeance or even bitterness. Rather, as watcher of the watchers, as key player in the drama of her own life, she chose to stay on the streets because it was her duty to observe and report. Quinn's interview, in many ways, can be read as though seen from the perspective of her own watchtower, from the time she first "went in" to the day of this interview as she waits for a bed so that she can get some sleep. In this next excerpt, patterns are drawn out to illuminate this central role that Quinn has taken on in her own narrative description of her life.

M: So what was that like, when you were living on the streets?

Q: You mean what did I dragnet?

Q: Well that's basically what I was doing.

M: What did you dragnet while you were living on the streets?

Q: Yeah, curiosity seekers. Do-gooders that had no idea.

M: Curiosity seekers, so people would come up and talk to you, is that what you mean? People would just come up to you and try to help or just curious?

Q: Curiosity seekers.

M: What do you think they were trying to find out?

Q: If I was a hooker or not.

M: Oh, O.K. and the do-gooders?

Q: Wanted to get me off the streets.

M: O.K.

Q: I didn't want to be off the streets.

M: It was fine on the streets.

Q: Oh yeah. Very safe. My natives took care of me.

M: How did, was that the way it always was at the start?

Q: Oh, well I checked out society. I lived on the street. When I first arrived. I didn't go to welfare, I didn't go to disability, and I went to the streets. And I just sat in the same spot. Got a book to read every once in a while cause I had good eyesight back then and I was reading by the lamplight; streetlight. And it's changed now, everything's changed. Every place that I've slept, has changed. Where they're sleeping, the festival used to be above. And now it's bricked off. Well, I was protecting the festival and the cleaning lady.

Quinn presents a vivid image of being out in the cold, of engaging with others and creating an exchange between people on the streets. She is aware of who needs protection and who is just there to look and "do-good". She is aware that the street has changed; places of comfort and protection no longer exist, or are not where they used to be. Nothing is familiar. This is

particularly poignant as there is no sense of home, in whatever sense it was once experienced. This is also a bit jarring to consider, given the emphasis of familiarity and sense of cohesion as contributing factors to mental health, especially for those who experience dislocation of time and place. Quinn lives now on the periphery of each of these worlds. She engages regularly with the formal mental health system, seeking relief in the form of a bed for her tired body. She lives also, though not as visibly by her own account, in the community, going over to the place where we met for the interview almost daily for a coffee or a few drinks. Quinn seems world weary now, having held "confessionals" for many years in her time on the streets and in and out of hospitals. She is still careful and cryptic with her knowledge, but allows some of it to be revealed:

Q: We don't worry about success.

M: O.K.

Q: We really don't. It's exposure is what I'm all about.

For Simon, accessing relief, even a bed for the night requires careful negotiation and strategizing; if he reveals too much, he will perhaps be confined for a longer period than he would like. If he reveals too little he may not be seen as a serious enough case to be offered the temporary reprieve of sleep. During one hospital visit, Simon is not seen as in serious enough need to warrant a bed. He has not convinced the admissions personnel of sufficient distress. Simon spoke of the trouble one could get into in a manic state, something he had hoped to avoid by presenting himself for admission at the hospital. In these excerpts, Simon makes visible the process of getting in and getting out of the hospital system.

S: Um, well the depression first manifested itself in, oh, I just had no interest in, like, my normal life and I was sleeping a lot I was just kind of dragging my ass through the day. I was going to work but as it got worse I started missing work and finally my family doctor

sent me to see the psychiatrist and he went through the gradient ratios of treatment, like you increase the dose and increase the dose until the person can function at a high dose, your system can absorb it and basically you wake up even at a high dose, you're back to yourself, and then tapered off it, it was like running up a big hill, of amitriptyline, and then down the other side until I was like back to normal.

M: On the amitriptyline?

S: Yeah, yeah, yeah, that was way back in '84.

M: Okay, had you had any, had you ever any given any thought to, if you heard about somebody who was chronically depressed? Or had any kind of mental illness, before you had the diagnosis yourself?

S: Yeah, my father had what was known as referred to as endogenous depression, which is, the theory is that it's a chemical imbalance so he was treated for that for a long time? Twenty years, I think, on antidepressants.

S: And then the next diagnosis or treatment was ten years later, '94 I had a span of no treatment for anything but, at the, uh, it was another psychiatric referral and she gave me a diagnosis of schizo-affective disorder and once again a treatment of anti-psychotic and an antidepressant both, yeah that was in '94. Oh yeah, in early April of the year 2000, I was trying to get a psychiatric committal and I went to first Queen street mental health, [aside] what the hell's in your cup…[laughs], and they wouldn't take me and I tried at Clarke psychiatric and they wouldn't take me. And then I ran out of time and I had to go through with a project I was working on and I didn't want to go through with it but because I ran out of time. I had to undertake it and I really didn't want to but I did it anyway. And if it's the one thing if I could undo in my life, I would but I can't because it

happened. And after that I had to come to Northern Ontario tell the same story and well they committed me right away.

M: So you wanted to get a committal, you were seeking a committal because…

S: Because I didn't want to go through the time portal.

M: Okay, and did you recognize the time portal as a contract or, how did you see the time portal?

S: Oh I knew that I had to enter it, I didn't want to, but I had to.

M: And what would have happened if you had gone to the Clarke or Queen, If they had admitted you like you wanted?

S: Then I wouldn't have had to go.

Simon also describes the effects of a "manic episode" on the body during and after the heightened state. He details the pleasant electrifying sensations of tactile hallucinations and the subsequent need for the body to recover "from the mind's episode." It was after one of these electrifying experiences that Simon sought relief from the mental health system. As he describes it, he "didn't want to go through the time portal." I have included here a longer excerpt from Simon's story as it describes so well his process of negotiating his way through the hospital system. This process has been a large part of Simon's life, although, by and large, he has lived creatively and fully outside of the hospital system.

M: What would have happened? Inside the hospital.

S: Oh, I would have been chemically sedated, like at the time I had not slept in, I don't know, a long time, I was going for three or four days without sleep so I was exhausted and psychotic. But I still believe this thing to be real ten years later, nine years later, but anyway I was trying to get out of it.

M: But you believed it to be real, but the structure of the hospital and the chemical alteration of the drugs would make it so that you didn't have to go through the time portal?

S: Yes I would have been saved from that, I know it sounds crazy.

S: Yeah, It's madness, it's absolutely madness.

M: But it, it did happen because your wife saw it too.

S: Oh yeah she saw it too.

M: So madness, going through it was madness?

S: Yeah, going through it was madness, going into it was madness.

M: And you would have recognized that if they had taken you in?

S: Oh yeah, I was trying really hard to avoid it.

M: So if you had gone to Clarke you would have been able to avoid this experience?

S: Yeah, all available help was presented just short of actual help, there was no help.

M: What help was presented?

S: Well they took me in and I had an interview with the psychiatrist and they said, hmm basically it's, you're not a danger to yourself or others, we can't admit you or confine you principally because we have more pressing issues with that same criteria, harm to self or others so, there was just no bed space. But there was in northern Ontario.

M: So they sent you here?

S: Well I was at the admission position, it was right there, all available aid was presented but no actual help was given because I could not get either a voluntary or an involuntary position with either at Queen Street or Clarke.

M: And being admitted at the time, how much of a change do you think that would have made? I'm asking because you said that you really, really didn't want to go through.

S: I didn't want to go, I didn't want to go.

S: Yeah when you go through one of these time portals, it's under water and I didn't think I was going to make it, the whole thing is a fight back, so it's fear of drowning.

S: No, I had to go through the time portal and, as a result, and after the, event…um…I was in so much pain that I had to get help.

M: Physical pain?

S: Yes…totally…totally.

M: What was the pain…tell me about that?

S: Um…well, if you can picture an interrogation with a bright spot light…picture three bright spotlights and they're all red and they're stuck inside your head…it's quite excruciating…it's fry material and that went on for too long…so that's why I had to…it was the biggest relief I ever had…I forget what they gave me…I had a very long sleep…when I came out of it…it was like…ahhhh…it's over…it was a great relief.

M: How long did that experience last?

S: It happened for sure, yeah.

M: How long did the experience last…the interrogation?

S: Oh, the interrogation itself?

M: Well, the whole time portal.

S: Oh, I was gone for a hundred and fifty seven years into the future…[laughs] of course…of course…I'm pretty sure I went the right way.

M: And how long did the sleep last?

S: Oh three days…I was gone for three days…

M: Okay, and you came out of it…and you thought…as you said…it's over.

S: Yeah…I thought I was dead but the pain was gone…Okay, but what I'm getting at is sometimes, if you can't get the help you need, you either kill yourself or you kill yourself, that's about it. […]

As Simon and Cassie have described, the hospital experience also involves long periods of recovery, daily routines and waiting to be released.

S: But to be able to function, like when you are committed to a hospital you basically will be released when the psychiatric team believes you are no longer a harm to yourself or others, so it's pretty. It's kind of an elastic definition what makes you well again is your treatment regimen…the treatment regimen and its success in controlling your elevated condition or depressed condition will determine the length of your stay, your incarceration. I really like *One Flew Over the Cuckoo's Nest* because it presented the well, Patrick McMurphy as a positive role in the mental health system.

M: Patrick? Jack? How was he a positive role model?

S: Yeah, well, he basically took over the institution, he was a psychotic who took over the institution and then became a martyr and died in the institution but, helped his friend escape, but the gap between all movies that are made about mental illness and the reality of being in a psychiatric institution is too large because it's just, it's tedious, it's dull, it's boring, you're just in there to get well, there's no entertainment, it's just boring, which I guess is the purpose of the thing, is to slow everything down and let the body recover from the mind's episode.

For Simon, there has always seemed to be a duality to the experiences of elevated moods, but as he states, there is a recovery from each episode of elation. In this last excerpt from Simon's story, he describes the experience of ecstasy.

> S: Benefits, oh yeah there are some benefits, like an elevated mood swing will produce quite a few benefits. Like, there are mood swings that are elevating, but the ones that are elevated, once you get to the plateau, then you've got like tactile hallucinations, like electrical, which last for days, your whole body feels it's being stimulated electrically, but it's a really good feeling. But after about four days of that you can't take it. You feel basically like you're being electrocuted, like fried, so it's good for a while, and you can have, your sexual appetite is quite high, and that's good, and you can have. I've had, many, uh, what can only be described as religious experiences and of course the conventional visual hallucinations that come at an elevated high and voices which are all, like when you cross over in a manic episode of bi-polar it's pretty well full blown schizophrenia, 'cause all the symptoms are there, so it's, so it has its benefits in terms of resolving spiritual equations, like your mathematics and your God conditions become parallel instead of in series.
>
> M: Sorry?
>
> S: In series, like they're hooked electrically, so they're running under the same current load instead of side by side, so it doubles up your experience
>
> M: Um, Can these insights be verified when you're on a more level plateau, the mathematical insights, the religious insights? Or are they part of, are they real? Say I was to get a dream, when I come out of the dream, it either is or is not based on factual reality.

S: Um, that's a good question, I'm still trying to verify that question but I can't because don't have the information.

M: Oh, because the insight is part of the experience.

S: Yeah, the information comes from the experience, the experiment.

M: Can you remember it afterwards?

S: Oh yeah, yeah of course.

S: My father said something one time which really I was really taken aback, I had spent the night in jail and he said, "well you shouldn't have any problem with that people with mental illness seem to do really well in an institutionalized setting". And that is the thinking, if you are, if you have a psychiatric diagnosis you can function well in jail or in hospital because you're just regimented that way to incarceration, and maybe that was from his experience of working in the jail for thirty years, is that those people with a diagnosis do function well inside.

4.4 Making Meaning out of Diagnosis

Brent's experience represents the difficulty in being understood and in being heard beyond his immediate symptoms. What Brent describes is the process of having to tell his story again and again to different people. Brent's story makes visible the ways in which mental health services are delivered on the basis of behaviour; his story also makes clear the arbitrary nature of deciding what behaviours mean. For one, laughing might be inappropriate, for someone else, laughing might indicate a return to health. Having been given a diagnosis, many people described ways in which their interactions and behaviours were now read as part of their mental

health condition, with expectations and limitations of the diagnosis. In this brief excerpt from Brent's story, he describes:

> B: Yeah. Okay, so as far as treatment, it's mostly just been medication. […]
>
> B: Yeah, until I came here and then, yeah, until I got to see a psychiatrist and I got to see, I got to see a therapist for a while. One lady, she was good and then I got this guy one time and one day I laughed at one of his jokes and he said, "You're fine. You don't need help anymore. You must be alright." I think he got fired or he got raked over the coals later on.
>
> M: Oh.
>
> B: 'Cause I told someone one time, 'cause I laughed, he thinks I'm fine.
>
> M: Oh. That's interesting, yeah?
>
> B: I said, I mean I can't laugh because I'm depressed? I just didn't go back to see him, I just, I laugh once and I'm perfectly all right.
>
> M: Yeah.
>
> B: Yeah, you don't need help anymore. Like, you're depressed, you're not stupid. Even when I was in the hospital, I met another patient there and the nurse came in and another mental health patient lied and said this girl had done something. This girl had done something in the past but this time, she didn't do it. You know, you get assigned a nurse when you're in the hospital, so I told my worker this other girl told her worker, right? And the nurse came over and apologized to her because, you know what? Just because she'd been causing trouble all the time, they didn't bother to check, they didn't ask anybody else. They just assume and they gave her heck. I said, "No, no."
>
> M: So that happens a lot?

B: That happens at the hospital…

M: Making assumptions?

B: Yeah, it does.

M: Okay, so there's a certain way that you're expected to act if you're depressed?

B: Well there's certain things that are average but not everybody does the same thing.

M: Yeah.

B: Yeah, but they take the average most of the time in the hospital. The counselors don't have time really to, there's a lack of time in the mental health system, you know?

4.5 Summary

The group of consumers and survivors who participated in this thesis do not represent any specific point of view. That so-called mentally ill or mad peoples' experiences were considered at all let alone qualified to add to the literature on mental health and madness is a relatively new phenomenon. The individual stories and experiences identified specific issues that were common to more than one of the participants but each story remains unique and personal. Throughout the process of listening to the interviews my perceptions of the mental health system and madness have been altered to some extent. One of the most significant findings is that people navigate through the system according to their needs and that they become experts in the delivery system learning the culture of the mental health system in much the same way that mental health survivors, those who sometimes choose not to align themselves with psychiatric services but with each other, cultivate meanings and currency within alternative systems. This is discussed further in Chapter Six.

The following chapter, Chapter Five contains analyses and discussion of the interviews with the group of stakeholders and caregivers. The interviews with the consumers and survivors serve as a backdrop to the next group of interviews. Having heard from Cassie, Simon, Quinn and others about their experiences as patients in the mental health system, the next group of parents, service providers, counsellors, social workers, psychologists and psychiatrists describe the work they do and the conditions under which they work. Some describe historical understandings and treatments of madness and this correlates to the discussion in Chapter Three on psychiatric history in Ontario. In this chapter, family members describe caring for loved ones and coming to terms with what this means for relationships.

Chapter Five: Stakeholders and Caregivers

"*The next five years was, 'certainly there must be a cure for this, certainly it's not permanent'* " (Collin)

5.1 Introduction: Coming to Terms

The caregivers and stakeholders interviewed for this thesis constitute a diverse group in relation to their proximity to people considered to be mentally ill or mad. The group is comprised of one parent, two partners, one sibling, one pastor, two Anishinabek traditional elders, three social workers, two psychologists, one counselor, and two psychiatrists. Their experiences span seven decades, with one participant describing the training and practices of psychiatrists of the 1960s and 1970s, many of whom had their psychiatric training during the Second World War at a time in Canada's history when psychiatric experimentation inside and outside of the country was rampant. The questions asked of this group were designed to make visible experiences of delivering services or of assisting with the care and management of people within the mental health system. What emerged were unique and rich stories of personal reflections, philosophical and ethical dilemmas and sometimes heartbreaking family decisions.

Each person interviewed situated him or herself differently according to roles, language, culture and power. Sean, a social worker, found ways to creatively help clients by accessing descriptors beyond the bounds of formal diagnosis. Julie works in an institution that is particularly hostile to people with mental illness or madness and she describes some of the barriers that remain. Collin, who opens this chapter with a quote about caring for his daughter shares a poignant, hopeful and honest story from within an emergency waiting room and from

within his own home. The themes that emerged from these interviews are, as in the interviews with survivors and consumers, seemingly limitless. A few themes were selected for particular salience and representation of some of the experiences of being a parent or professional caregiver in the contemporary mental health system in Ontario.

In interviews with Sean and Dave, both social workers, the idea that diagnosis happens often in a particular setting mingled with Collin's poignant wish—that there must be a cure, otherwise what would be the point of the treatments and waiting rooms. This chapter brings back into conversation the historical, asylum era schism between custody and cure. The schism remains in the community model. It has not adequately represented the kinship models of traditional wisdom. Instead it has insisted in caravan fashion to replicate the custody model, maintaining the distinction between the one who is mad inside and the sane expert. In the previous chapter almost every participant described some form of post-diagnosis social isolation. Maggie described the pain of witnessing her sister narrowed into a tight term she could not even say and Collin, for a while, hoped against hope that a cure could be found to return his daughter to who she was.

Mental illness and madness are corralled and held up for inspection in these places; they are given names, treatment protocols and bodies to rest within, forever changing the host. The people who are brought to these places or who submit to inspection are hoping for something. Madness is not without its pain and terror and when there is nowhere else to go—madness is not without its danger—the mad find themselves in these places. The people they encounter are not without their histories and insights; these are not voiceless and mindless robots. The parents, nurses, doctors, social workers and friends find limitations within the diagnostic language and

they are acutely aware of the stigma that still rests on these bodies, in the waiting rooms, despite all the talk. There are different kinds of being mad. Reason still marks out its limits.

The concept of seeing and speaking about madness in particular ways in particular places emerged as a theme tied to language and visual representations of madness. Sean, in his role as a social worker upsets the power of diagnoses and prognoses relegating them backstage, where their only function is to provide entry into the mental health system and its concurrent funding processes. From a critical perspective diagnosis can be seen as a gateway drug. Mischa's perspective is less critical. Mischa stands firmly behind the diagnostic process and the professional affiliations established and maintained through it. For Mischa the terminology that describes severe mental illness, mental health and mental wellness are tools and representational placeholders for the people for whom her interdisciplinary team develops a treatment plan. Tim sees madness as an imbalance. Restoration to balance is, in Tim's perspective, the cure. Each person, for Tim, has a unique walk and imbalance is part of that walk. The healer must first heal herself through a return and maintenance of balance. The various perspectives, through many different experiences are brought into conversation in this chapter.

5.2 Cures, treatments and waiting rooms

Tim identifies as a member of the Loon Clan and as part of the Ojibway Nation, and he uses traditional healing methods to treat what he considers to be imbalances. Tim met with me in his office to discuss his practice and philosophy of what is called mental illness. While Tim did not dismiss the term mental illness, he continued to refer to imbalances caused by tricksters. Tim's story of his experiences with these imbalances begins with himself and is told with a lot of humour. Tim's approach situates all forms of disharmony within the self and sees this

disharmony extending toward and in relationship with other people. This is not vastly different from the psychiatric approach; indeed, there are holistic, wrap around and client centered models in psychiatric and mental health practice. What is significantly different about Tim's and other community, kinship and clan based approaches is the recognition of experiential wisdom and traditional hierarchies of knowledge.

> Tim: Well, one of the most important things in working with the imbalances in people is to understand the nature of love and humility and the nature of bravery and the nature of wisdom. Once you understand the nature of love you arrive at your truth. Once you understand your truth that's how you begin to balance your life.
>
> Moira: What is the nature of love?
>
> T: It's the absence of the fear. There's no fear in love. That's the difference between love and in fact real love is consistent over time, over days, over years and there's no fear in that. That's real love and bravery is meeting your foe with integrity. Your foe could be your own anger and you gotta meet that head on and define what it is and let it go. That is being a great person and humility is understanding that you're only a small part of nature just like there's no two Moiras, there's no two Tims there's only one of each that's humility and when you do that you understand you have a very small role in the overall scheme of things (pause) but you can influence your environment either for the worse or for the good it is up to you.

Prior to our interview, I took tobacco to Tim and gave it to him. I then asked him for his time and his knowledge. Tim carries the knowledge that has been entrusted to him by his elders, and his pipe-carrier status signifies this trust. Tim's knowledge is often disseminated through formal teaching ceremonies and through his work as a teacher and counsellor. Tim's experiences of

helping people with addictions and other issues involves traditional use of medicines, visions, dreams, fasts and feasts and sweat lodges. I was already familiar with many of these practices, having attended both Celtic and First Nation's ceremonies for many years. Tim's teaching was nevertheless new to me as his position came with it an authority and disciplined practice that merged his traditional teaching with formal education. Visions, hallucinations and dreams are part of the natural order of things in both Celtic and Anishinabek traditions and our conversations prior to the interviews had often centred on a common sense of the absurdity and the mysticism in our respective traditions. As Tim explained it, at the root of disturbance or disharmony is an imbalance between love and fear, a condition that spills over into other relationships—with relations, neighbours, one's community and for some, with the creator as well.

> T: I started this in 1983, how I classify mental illness is people who have addiction problems, people who have violent tendencies, people who are dysfunctional in an extreme way, they need to restore balance in their lives, that's how I define mental illness. Basically I don't do any healing ceremony unless I'm asked, so when you're asked people give you the authority to inquire about whatever issue they're working on and from that I can devise a healing plan for them and so it seems to work pretty good using that method of accessing clients or people to work with. In terms of policy, like you are asking, well the only policy that the elders that I work with, the elders are, I refer to them as our spiritual masters and they only had two policies. One policy is that you shouldn't drink if you're working with the spirits. And the second policy is, uh, informing women who are on their time not to participate in the ceremony because women have a lot of power and they can hurt your ceremony and you included, because

> they're cleaning themselves of their negative energies and sometimes they don't know how to dispose of that energy in ceremony and because they haven't many of them haven't been practicing their culture and they don't know about that energy and in the process of not knowing, they could really hurt you.

Tim's belief is tied to energies and balances of fear and love; as well, Tim alludes often to specifically feminine and specifically masculine traits and strengths. For example, in some cultural practices, women sit outside of the sacred circle. This exclusion is acknowledgment of the power of feminine energy as well as the process that women go through during their cleansing time. Tim's explanation for violence and disruption is due to an imbalance in energies. It is a simplified diagnostic process, encapsulating with only a few words a range of human experiences. The healing feature of Tim's approach is in his recognition of the uniqueness of each person and his belief that person has his or her own walk. Experience and the honoring of traditions count for a great deal. Tim uses medicines to acknowledge that he, being made of the same substance as those he helps, is susceptible to imbalances. His efficiency as a healer is measured in the humility of his walk—he does not walk alone and when he does walk with another it is in order to direct a harmonious rhythm that plays a part in the healing of wider concentric circle of family, community and beyond. Perhaps most effective of all in Tim's approach is in the narrow distance between healer and sufferer and a belief that makes room for wide range of mystical experiences.

> T: And my bundle includes the medicine wheel, the medicines, I have four medicines that I use, I use tobacco, I use sage, I use cedar, and I use sweet grass in all my ceremonies. And those medicines represent my relationship I have with the spirit world and so people learn to know you really well before they disclose to you about whatever issue they're

working on and so those medicines signal to them that I've done my work among the spirits and I know what I'm doing.

M: Okay, it's very interesting it makes me think of the "physician heal thyself" that you have to get right yourself before you can, is that sort of like?

T: Yeah, it's almost the same thing because you have to walk the talk, before you can actually do the work.

By contrast, hospital diagnoses, through the established authority of the medical system, the DSM and the constant experimental work of pharmaceutical companies present a system that is hard to resist especially in the face of the unknown and mind boggling array of possible illnesses. Nothing makes clearer that psychiatry and the mental health movement form a vast industry than a statement of acknowledgement in its own publication, the DSM-IV. In its introduction, the American Psychiatric Association notes, "To maintain open and extensive lines of communication, the Task Force on DSM-IV established a liaison with many other components within the American Psychiatric Association and with more than 60 organizations interested in the development of DSM-IV"(APA Introduction xvi). A few of the 60 organizations so interested are listed including: American Health Information Management Association, American Nurses' Association, American Occupational Therapy Association, Group for the Advancement of Psychiatry, the World Health Organization and the National Association of Social Workers (APA Introduction xvi). As regards the official lexicon of the industry, in the DSM-IV the APA promotes at every level "an official nomenclature" which "must be applicable in a wide diversity of contexts" as "it is used by psychiatrists" and other professional groups and as well "must be usable across settings—inpatient, outpatient, partial hospital…and with community populations" (APA Introduction xv).

As regards the use of the term "mental", the authors claim that "the term persists in the title of the DSM-IV because we have not found an appropriate substitute" (Introduction xxi). The DSM-IV defines dysfunction, as it is described in a diagnosis of schizophrenia using a set of deficits or "the degree of difficulty that some individuals with schizophrenia have with activities of daily living as well as the ability to acquire skills in psychosocial rehabilitation" (DSM-IV 304). These and other difficulties with intrapersonal and interpersonal relationships are thought to be at the root of mental illness, according to the DSM-IV.

Allen Frances, M.D. chaired the task force on DSM-IV. He has also been one of the most outspoken critics of its successor DSM-V. In the preface to his book, *Saving Normal: An Insider's Revolt Against Out-of-Control Psychiatric Diagnosis, DSM-5, Big Pharma, and the Medicalization of Ordinary Life* published in 2013, Frances laments on the ethical quandary in which he found himself in 2009. "Sometimes" he reflects "you can get into a whole lot of trouble just minding your own business at a cocktail party" (Frances Preface). Frances was just there "to catch up with some old friends" as he had "for almost a decade…been pretty much a dropout from psychiatry—retiring early to care for [an] ailing wife, to babysit [a]mob of grandkids, to read and to be a beach bum" (preface). Frances' experience with the *DSM-IV* and his work "on the periodically updated editions of the *DSM*" made him, he says, "wary about the risks inherent in any revision" and concerned that his friends were "new to the game and excited about their role in preparing *DSM-5"*(Preface xii). He was most concerned, he says that "they intended to add many new mental disorders and to loosen the rules on how to diagnose the existing ones" (Preface xiii).

In "A debate between Allen Frances and Robert Whitaker" a featured blog on the Mad in America webzine founded by Robert Whitaker, Frances and Whitaker continue a debate, at

Frances' invitation, which began at an earlier conference in Los Angeles (Whitaker "A debate"). As well as the webzine, Whitaker is the author of several books including *Psychiatry Under the Influence* which is described as an investigation of "the influence of pharmaceutical money and guild interests" which have "corrupted the behaviour of the American Psychiatric Association and academic psychiatry during the past 35 years" (Whitaker "About Us"). Frances begins the debate by acknowledging Whitaker's criticism of psychiatry and his respect in this regard and claims that he, Frances is "no defender of the APA" and that he has in fact "harshly condemned its incompetence and financial conflict of interest in producing a poorly done DSM 5" (Allen qtd. in Whitaker). Where the two part ways, is in Whitaker's assertion that "the moment that the APA adopted a disease model for categorizing psychiatric disorders" was the moment of "a fateful decision" and this "certainly wasn't one made by pharmaceutical companies" says Whitaker (Whitaker "A debate"). Whitaker's position, that the APA *as a guild* "in competition with other professions for patients at that time" challenges in its complexity, the simple perspective offered by Allen, that although "the APA is an easy target…the real gorilla in the room is Big Pharma" (Allen "A debate").

The historical analyses make clear that the earliest psychiatric and health entities have always in some respect competed for patients re-working people as incorrigible prisoner destined for custody or labour, or as patient destined for death, custody or various forms of cure and care. They were organized according to institutional suitability but also according to the self-replicating needs of the institutions themselves. Taken together, the power and language of psychiatric and mental health systems or guilds and their complicity with pharmaceutical marketing present a web of confusing messages. The diagnosis, which is sometimes nebulous

and often resisted or only invoked when necessary is the only way to access formal care and this is presently all that is recognized in Ontario.

This was the system Collin chose. With few options presented and with his expectation of a cure, he sat in the waiting room while his daughter, who, according to a friend, had not slept for days, entered the mental health system. Collin eventually became the legal guardian of his adult daughter after she was diagnosed with acute onset, drug induced psychosis—schizophrenia. The irony is that Collin works in the field of mental health and addictions. He has had many challenges in his life. Years ago, Collin introduced me to his teenage daughter and then, a year or so later, he shared with me that she had experienced a drug induced psychosis as a result of using Ketamine. The psychosis, often temporary, did not pass. As part of the interview, Collin described how his daughter was judged by some of his family members as a girl who had brought this on herself. As I sat at the kitchen table across from Collin, he told me his story. He told me how this drug induced illness had affected himself and his family. Collin was expressing his personal loss. Here is what we wished for. Here are the roles my daughter was supposed to fill. She had been given back to him as someone who needed him all over again.

For Collin, what happened since his daughter's diagnosis of drug induced psychosis and permanent injury necessitated a reorganization of his relationships with his daughter, his wife, the hospital system and his extended family. Collin alludes to the social organization within his family which often excludes his daughter. In Collin's daughter's case, there doesn't seem to be a way out, he says, although, he says that going to the centre helps to get her out. Collin also mentioned that he sees many people at the centre that have no family support, and that at least his daughter has that. During the interview with Collin I could sense his sadness, his disappointment, and his guilt at feeling disappointed. In no other interview had I heard such a

mixture of loss and hope. The interview took place at Collin's kitchen table. We make small talk and he offers me a cup of coffee. It is bright. I have had conversations with Collin before, but not about this. Collin talks about the difficulty of seeing his daughter, who I call here Sam, and other people with mental illness being treated with indifference and cruelty.

Collin's story begins with a sense of disorganization of family roles. I have not specifically asked this question of Collin, but it is where the plot of the story begins to take shape as I listen to it. The disruption of Sam's expected trajectory into adulthood and independence, and the delayed term of parent for Collin, are among the phenomena that show themselves most clearly at the outset. Collin makes clear his own tensions of being a father who has to let go, but not abandon, his daughter, first to the world of her own choosing, and then to the psychiatric system. He re-enters his parental role as a legal guardian.

> Collin: Okay, my daughter's thirty-two right now and she was first diagnosed as a result of a drug overdose back, it's got to be ten years now. Ah, there were behavioural problems which we now understand were probably manifestations of schizophrenia at that time but we understood them, (Sam's mother and myself) as behaviour and character traits that were not conducive to family living, running around, staying out late, was an A student up until grade eleven, grade twelve, good athlete, smart as a whip, always tried. You must understand that throughout that time I was dealing with a cancer episode and had been hospitalized for a great length of time so we now understand that there was probably some abandonment issues with S at that time which were not dealt with, not seen. She finally left the house and was, she went to Toronto to work much to our delight to get her out of town because there was troubles with the law, troubles with being promiscuous, troubles with alcohol, drugs. And she left to go to Toronto and at twenty-

one years of age we were kind of glad to see her go. If you're going to act like, go do it, you're a grown woman now. So as a result of this Special K overdose we received a call one night that Sam may need some anti-depressants, from her roommate and we asked why. She had been curled up in a fetal ball in her bedroom in that apartment she was staying at, for eight days, nothing by mouth, no water, did not go to the bathroom, just in a comatose state.

M: Okay. What was your role in all of this, as a father obviously but…?

C: My role was as a father and trying to care for a daughter who we had not abandoned but ah, allowed her to go out and, certainly didn't have a hold on her or anything, to say about what she was doing as a grown woman at twenty-one, twenty-two years of age and coming back to us as a disabled child.

Collin is trying to make sense of the ways in which mental illness has disrupted the expected trajectory of his daughter's life and that of his own. The relationship between Collin and his daughter is now a formalized one in which he is responsible for her care. He describes his eventual acceptance of this role, but he is still Sam's father and it is hurtful to see her shunned by family members at the same time as he watches her become immersed in the formal organization of first the psychiatric hospital and then community homes and support systems.

C: So, you don't walk into emerge and get diagnosed with a diagnosis and everything's hunky-dorey and you live the rest of your life. It was the next five years was certainly, there must be a cure for this, certainly it's not permanent, and certainly we'll try some medications. So it's a process. So that's when the process began and drugs are the first line of defense for doctors. It's not like television where they put people on a couch and start giving them therapy and people that go to a hospital; they're subdued with certain

drugs, other drugs to straighten out their thought processes. So there was a period of time of hospitalization back to our home. We became the primary caregivers, she lived here at our home and that went on, probably four or five different relapses. Why would a person relapse off their medication?

So at that point I become the secondary decision maker. It's not that I make the decisions for Sam, I interpret what Sam would like if she was well, and I don't have the opportunity to have my input or have my opinions about her care. I have to realize what Sam would want if she was well, for herself. That, that's a difficult process. So we started this drug trial which she didn't like and she didn't like the limitations of being on a community treatment order and the purpose of the community treatment order is to keep a person out of the hospital and to keep them inside the community, so she was actually brought back to our home at that point and tried this program on half a dozen occasions. Mental health housing—that's a whole other issue, what's available for people who are at risk, so to speak. Don't have the skills to live on their own or they are, and there certainly are impaired people who are on heavy duty psychoactive medications, are, have impaired judgment, certainly limitations about living with strangers, because it's usually three or four or five people living together so Sam's experience with independent living although she had been placed on ODSP at that time and a strict budget that she could afford to be placed with two elderly ladies in their seventies. She felt like she was trapped in her own little bedroom and didn't dare go outside into her own home.

M: Yeah.

C: So us forcing her to do that was not therapeutic by any stretch of the imagination. So after four or five tries at different places we finally decided that she would come back to

our house and she took over the top story of the house. So were we her caregivers? I don't know. Ah, she lived here, she did her laundry here, she contributed to the normal household chores, ah, she reported to us about where she was going, what she was doing, who she was seeing, tried to take advantage of some of the resources here in the community, like peer support. I attended myself and to my own—the way it looked—going down there looking at it, it was several street people going in there for coffee and kind of, smoke cigarettes and drink coffee and that, that's normal for people who don't have the family support, to go downtown and just smoke cigarettes and she was actually trying to get her life back in order…she ran the canteen up at the Algoma Hospital for three, six month stretches. During that stretch five years ago they were seeing her daily, they were giving her meds daily, they were visiting the house, they were seeing ah, certainly talking to B [Collin's wife] and I, her plans were made for the next day, the team was actively involved and there were some episodes of running out of medications and not having bus rides and, just daily stuff, stuff you wouldn't expect to be doing with a twenty-five, twenty-six, twenty-seven year old woman. […]

C: Seems every time you see some light at the end of the tunnel, it's not the end of the tunnel.

M: Hmm.

C: It's taken a long time to realize this is life. Is it going to get better? Ah, it's never going to get better where we're back to the point where we were ten years ago. We'd had a terrible, not a terrible toll, we've had a toll on our family environment, our family life here and, especially having a younger sister within this home, and at seventeen, eighteen having all the same problems that S was, you know. And the self-assertiveness and being

a good student and ah, my youngest daughter treating S like it was still a character and behaviour and not understanding that it is a mental illness or a disease and there's nothing S could do about how she perceived her sister or me or herself. Her reality is different from everybody else's reality that she lives with or that she's involved with.

M: Okay, so, what were some of the reactions people had when, when, for instance, your other daughter, other family, close family that would know about what had happened, what were some of the reactions that you've had?

C: She is the oddball. She's separated. When they see her and they come over at Christmas-time or we go over there, S sits quietly and, like this [gestures] and ah, they treat her like she's an idiot and she's not an idiot. She's has a mental health problem. So, and that, that's it for people who don't know anything about mental health disease. People that present as stony faced or quiet or perhaps they take in, and this is true with kids that are, um, what do they call the kids that are…?

M: Autistic?

C: Autistic children. Too much sensory input, sitting in a room with eight or nine people. S's concentrating on the buzz that the refrigerator's making because she hears that and that is causing her discomfort. She's not listening to the conversation or able to participate. The hum of the fan or the fact that there's a piece of dust up there and focuses on that.

M: Yeah.

C: That's her reality. So my family treat her, my dad has come around, he doesn't anymore, he accepts Sam for what Sam is and maybe the rest of the family is coming around because we just don't tolerate it, we don't, if you don't want to visit Sam, but I

think that's, all my brothers and sisters were living here in the community, it's not like they came rushing to support us and, with that. If it had been cancer or a broken leg or a car accident or something else, they would have been at the hospital, you know, staying there overnight, holding her hand, and trying to comfort her. True?

M: Yeah, that's awesome. So are there any other final…

C: Summations?

M: Insights about what this experience has been like or…?

C: I wish it wouldn't have happened, Moira. Like any other disease, I wish it wouldn't have. We cope with it. We live with it. We do the best we can with it. Sometimes we have good days, sometimes we have bad days. So it's like any other, it doesn't matter if it's physical or mental, things happen to families. So, in summation, I just wish more families would become involved because they are the people that can actually make a difference, you can't rely on doctors, nurses, act two teams, strangers who are doing this for a living, to create results. That's gotta be done in a family unit and that can be between—you know, my son has taken steps since he's moved back to town, has taken on a responsibility role because he earns a living, he has a girlfriend, they have a house. That takes a load off not only B and I, but that's an extension of the family and he treats her well and treats her like a human being. Isn't that what any of us only want, to be treated like a human being? And Sam can go to her brother's now and be treated, and she goes down to the YMCA and she goes to school and she's treated like a human being. Hospitals don't do that.

Collin described the process through which he eventually came to accept his daughter's diagnosis. The complexity of living with mental illness or madness, as Collin has made visible

involves a process of changing roles, trying different approaches, negotiating relationships within and beyond the hospital system. The hospital system maintains its status as the nerve centre of mental illness and madness; it is the place where many people enter the mental health system.

Maggie is a colleague known to me through a few mutual acquaintances. I knew that Maggie's sister was accessing community supports through a work program that I had been involved in a few years prior to meeting Maggie. Initially, having met Maggie with her sister on several social occasions, I meant to ask her sister to participate in the interview. Maggie explained that her sister would find this difficult and it would cause her discomfort and that she, Maggie, would like to participate in the interview. Maggie makes visible the narrowing of focus that comes with a diagnosis. Her little sister was diagnosed with schizophrenia, a word she refuses to say in our interview, choosing instead to spell out the word. She explains that her sister is caught underneath the medicalized perspective, as if from here onward her actions, thoughts and behaviours, if these deviate noticeably from rational functioning will pass under this gaze to be accounted for. In a brief excerpt from Maggie's interview she explains through tears the difficulty she had in seeing her sister this way.

> Maggie: My sister had difficulty with adapting in the school right, so she had the learning disability already sort of assessed and then, she needed more help so some family friends who were part also part of the health community referred her to Dr._____. I don't know how it developed but he started seeing her and then, I don't know when there was a diagnosis of, whatever you want to call it, um, the um what's it called s-c-h-i-z-o-p-h-r-e-n-i-a.
>
> Moira: Schizophrenia?

Maggie: Yes, but I don't know when that was diagnosed but now I know. I had to fight with her to take her pills

Moira: And she, now you spelled out that word, is it hard to pronounce or...?

Maggie: I just find it very it's like, I don't know, that's not my sister. I don't see her that way. So that's what the world or health professional see her as, but that's not how I see her. I think that's a very limiting label to her. Because she's my sister I just don't see her that way and it's a hard word for me to pronounce (laughs) I just don't see her that way but there was a diagnosis from the health professionals.

Moira: Were there any other diagnoses?

Maggie: No well last year there, when my father was diagnosed with cancer we asked her to see, or asked someone, a psychologist, to see her so that she would be taken care of right? So he or she said that she had another diagnosis when they're isolated in their world. I don't know what the word is it for it. I'm not sure if these are accurate labels or not but that's the word that they use. So that's been my experience that like, it's been for lack of a better word it's been a continuum. I've seen in her such a remarkable improvement I don't know why she's still taking pills but maybe you know that's what she has to stay on to stay better to keep well.

Maggie: Well because she was born with the developmental delay, she was born with the umbilical cord wrapped around her neck so that was, that caused her to have physical limitations and then she had a difficult time in the school system because she felt very isolated by others, and then that caused her to feel emotionally hurt as well. Before we knew that she had suffered this brain damage, I remember not understanding her, perceiving how it was hard for her to maybe get jokes, for example, she didn't find them

> funny, there was always something a little bit off, she had difficulties in school and they started sending her to get assessments, blah, blah, blah. My mom would be better knowledgeable about what was going on there because I was pretty young, probably in my teens early adolescence, teeny bopper, but one of things that we thought or at least my parents thought was happening was that she didn't want to learn, that she wasn't motivated to learn, she had no ambition or desire to do well in school, so we thought oh she's just being whatever and until we learned that it was not her fault.

It was clear in listening to Maggie that she felt there were significant oversights in the description of her sister that the diagnosis had provided. Beyond this, she saw that access to supports relied on the diagnoses. These tensions existed for several of the interview participants.

Layla often had to take her partner to the hospital for emergency psychiatric treatment. Layla's partner, with whom she had a long term relationship, died not long after the interviews were completed. I know Layla through a long term work relationship as well as through several mutual friends. I had been aware, prior to inviting her to participate in the interviews that the care of her partner required a lot of her; she was called from work from time to time to take care of her and she had become an advocate through her knowledge of the mental health system.

> Layla: It can be, it's really rough at times, very rough. It's debilitating. You get tired, like you're tired enough from work but when you come back to a partner who's in the middle of an episode, it's very tiring. You don't get rest because you have to stay up and see what's going on. Then sometimes escort them to the hospital. Gotta make that call. Then at the hospital you're waiting six, twelve hours at a time and she's still in the recovery room without a bed so…

Layla is particularly critical of the services provided. Her experience has been one of waiting—waiting to be seen by a doctor and then waiting again to see if this treatment or medication, this time, will help or make things worse. Layla and her partner have waded through this process again and again over many years. In these excerpts, Layla describes the careful balance of accepting the diagnosis, but also being aware that there is a piece missing, a shadow side to the accuracy of diagnosis. In her partner's case, the diagnosis was schizophrenia, and there were many medications prescribed over the years. Layla saw herself as an advocate for her partner both in terms of accessing services and as well, in terms of defending her partner from the taunting voices of her former abuser. In these next excerpts, Layla describes getting support, the perceptions of specific types of mental illness and madness, and she also provides a perspective of the day to day experiences of managing the symptoms of mental illness and madness.

M: Okay. And you mentioned also about, there's a block to people getting, accessing care if they have more severe mental illnesses. Is there any more than you can say about that?

L: Ah, I think that's everywhere I go, especially with schizophrenia and the bi-polar. If they've been recently episodic, they don't seem to be able to access as many services as they need.

M: How so?

L: Because sometimes it's different. Sometimes they're more resistant to taking their meds, they're not as compliant as maybe someone who's depressed so there's that difficulty and I think there's still people's perception that you know, they could flip out at any time. I think that's another barrier.

M: Yeah. That's a really interesting point that people that are more depressed, people who are depressed are more compliant, yeah.

L: Yeah, they are.

M: So can you, yes they are? And can you say more about people who are on the other end of bi-polar or they're in that phase, they're schizo-affective and they're not so compliant?

L: Well, I think side effects of the meds, the biggest thing I've heard from my own partner and from people that I know personally, they don't like the side effects of the meds especially weight gain for women. Weight gain.

L: An example? Ah, somebody who weighed 115 pounds is now 215 pounds.

M: Yeah, okay.

L: Anti-psychotics, another one is sleeping too much like (inaudible), feeling lethargic, no motivation, like feeling more depressed on the anti-psychotic than anything. And they like feeling the manic or the high energy level of the episode.

Maggie and Layla are careful that the diagnosis does not sweep up the entirety of the people they know beyond the diagnosis.

Dave has a unique perspective of the place and power of the mental health system. A social worker, his recollections begin just prior to the 1970s, a particularly interesting period of experimentation for social workers and for sociologists. Dave did not begin his work until the following decade but tethers the influences of the 1970s to the practices of the 1980s. As a child and youth worker employed in group homes and institutions around this period, I could identify with his recollections of the past. I recalled staffing patterns meant to mimic family dynamics, one the mom, the other the dad. I remembered group home residents being physically restrained

by several staff members, hot seats, staged confrontations and blurred lines of intimacy. I was once held by two teenagers only a few years younger than I was while the director hit me with a wooden stick—just a prank. I heard from other colleagues about even stranger practices; we could not see that it was awful because our training, our textbooks, our manuals, through language, had prepared us for the abnormal and the bizarre. I recalled this period vividly as Dave spoke in long descriptive responses to the questions I had for him.

Dave brings this period to light, effectively illuminating the social and economic re-organizing of the 1980s and 1990s that came on the heels of the 1970s therapist-centered, sun-dappled encounter era. The 1970s were the halcyon days of psychiatry. Talk therapy and liberal use of drugs—prescription and non-prescription—collided with an indulgence of self-exploration, mind expansion, full disclosure and experimentation. The decade that followed was rigid in comparison; on the one hand, in terms of institutions, it was full of rules, accountability, boundaries, and definitions. As well and at the same time, revealing, talking publicly and confessing—in literature and other media—continued to boom into a lucrative helping industry of professionalized, television analysts. Meanwhile, the sails of the community mental health network were tacking also in another direction.

Dave is one of many people interviewed who discuss the allotment of funds to specific areas of mental health care as being a constraining factor in helping people. As he makes clear, lack of funding can leave professionals feeling chained to a model that does not allow for creativity or thinking beyond the medical model. Medically sanctioned diagnoses get funding and are attached to treatment protocols, including pharmaceuticals. Furthermore, the seriousness of the diagnosis ensures the need for professional assistance. The interview began with a discussion of Dave's place in the mental health system.

Dave: Oh definitely. My function, my role changed. My position right now, I'd say is not in the mental health field per say. Elements have something to do with mental illness but probably more do to with mental health. I functioned as a psychometrist, psychological associate, mostly therapist for thirteen or fourteen years in the mental health system. Over time there has been lots of change.

M: Can you think of anything that, even the distinction to be made between mental illness and mental health?

D: Yeah, that wasn't part of, I wasn't really interested in mental health system. It's called mental health system, it's really focused on mental illness. But when I first started it was really, it was a time when there was a lot of freedom to do things and there was, I wouldn't necessarily say a therapy culture, but it was certainly not as rigid or medicalized as it has become or it became even as I was leaving it a few years ago. When I first started, I'd say there was a lot of informal practice, a lot of people doing a lot of things based on, if you had an interest in literature and it was interesting practice, you'd follow it. A lot of people just did what they thought was best. And then as time went on, there was an increasing, I think, I'm not sure if it's precipitated by it, but it was, at least, it seemed to be, grounded in this idea we only have so much money and because budgets started to decrease, there became an emphasis on what were called seriously mental ill and because you were supposed, your services were supposed to be focused on seriously mental ill, illness became a real part of the equation. You looked at people and, were they ill enough, did they have a certain diagnosis, whether the chronicity was long enough or the severity was long enough and all these things just to get funding so it really, it became interwoven within your practice. A lot of time was spent trying to figure out whether or

not somebody should be seen by a certain person, not because of illness as opposed to the potential for success.

M: Okay. So what would happen with somebody (these are open ended questions), what would happen if someone came in and they didn't fit, they didn't fit the criteria?

D: Well, at first we had some freedom and it was, the government would never ever say, "You should not see somebody" explicitly. I mean, if you talked about details, those conversations rarely happened but it was just serious mental health. So if someone came through the door, over time the system starts to rearrange itself and, for example, if I had, when I first started I would see clients who had, who wanted to increase their self-esteem or just felt like it was a point in their life when they, it would be good for self-growth, I mean, it's so extreme now, and there'd be no question, we'd give services. But we set up intake processes where there were certain criteria that people would need to meet, maybe basically explain to people that this service is for seriously ill mental health individuals and that just infiltrates your, and a wait list is developed and your wait list just goes on and on and on. So the system starts to reformat itself so it would only allow a certain type of person to come in basically and, if someone was persistent enough, I guess they would get in, you know? But the question is really why because the services started to change so where somebody may want to just talk about something in a conversational way to increase their self-growth, that's not going to happen anymore. You're going to have particular therapies that are, you know, the best practices, very much focused on it, the systems of illness, you know?

What is apparent in Dave's insider perspective of the changes in the mental health system as he has witnessed it is the reincarnation of distinctions between people who can, in some formalized

way be designated as mentally ill, and thus in need of services. This is reminiscent of the cure or custody debate at the root of the early asylum system. At a time when the mental health system was made to justify or at least account for its existence through a rational process of services rendered, the institutional lens, at least, focused on serious cases only. This had mostly to do with economic policies or increasing rationalization of services, as Dave explains.

> M: So it was more medicalized? That was the change in the wind? In the past twenty years?
>
> D: You know, I really, from what I can tell it just kept on going in that direction. I mean, I'm not sure if it could get much more extreme. I was part of a service that had a limited amount of interest by the government because we saw everybody but certain identifiable diagnostic groups, so we did not see exclusively individuals diagnosed with schizophrenia. We did not see exclusively individuals diagnosed with eating disorders. We would see everybody else plus some who fit those categories and but, because we'd see everybody else and we provided psychotherapy, which was not considered of interest by the ministry or the government, we were always feeling, justifiably, that we were not going to get money for the following year and, in fact, that was the case. Our funding, when I first started, which was in '91, there was the Canadian Mental Health budget and there was the institutional budget. The Canadian Mental Health budget, actually, I don't think ever went up so it funded so many positions at a certain salary. By the end of, when I left, they could fund, like half those positions and the government, because we were providing what was considered a service that was focused or targeted specifically for a serious mental health group, like a diagnosis of schizophrenia, ACT for schizophrenics or case management or whatever, they would not fund us for more money, so new services

> were getting funding whereas the old services were kind of dwindling. And anyway, it's pretty clear where the kind of, which way the wind was blowing, right? Blowing in their direction.

In the next excerpt de-institutionalization, another pivotal re-organization of the mental health system beginning in the 1970s and continuing throughout the 1980s and 1990s, is discussed. As more people were let out or sent out of institutions, some, as Dave makes clear, were streamed toward the community mental health model. During the interview, Dave's critical analysis of the situation is clear. He has twenty years of experience and has clearly been attuned to the systemic changes. Adding a further layer to the analysis are the lived experiences of the mental health consumers and survivors who by and large discussed the poverty, the difficulty of finding work, the long waiting times, the experience of not being taken seriously. These too are the realities of the changes in the wind. It is not that institutional living was better, but that the reality just outside the institution, where many were forced to live, some already crippled and psychiatrized by negligent or abusive treatment, rendered them hostages to conditions that could induce mental illness or madness in anyone.

Many people, like Cassie, Holly and Quinn, each with a diagnosis of some form of schizophrenia, have ongoing interaction with the mental health system through the hospital. After care programs are a component of post hospitalization; after a relatively short stay, Cassie, for example, was discharged with a promise, legally recognized, to adhere to treatment orders. Constantly being tracked and monitored, she remains in the community as part of the new organization of mental health and madness. Dave discusses the changes that came about from the emphasis, and mandate, to focus funding on treating what were considered to be more serious cases, those with graver and more noticeable symptoms. I should have asked Tim, the Ojibway

elder, how someone with schizophrenia would be treated according to his praxis of restoring balance; I think his holistic model would be in harmony with Collin's lament for his daughter for inclusion beyond a smoke filled shared group home. It would perhaps also be in tandem with Simon's request to get rid of that hard 'k' that makes anyone who has that diagnosis seem untrustworthy. In this exceprt, Dave sets the stage for this conversation by situating the power of language in the nexus between funding and diagnosis; to get access to treatment, a diagnosis is required and once the diagnosis is provided, as Collin and many others attest, there is a waiting period and a trial and error period. At least this is so in the cases that would be considered, according to Dave's explanation of the system, more serious. Almost all of the people selected and invited to participate in interviews would fall into this category.

> D: I think they have, I mean, but I think it depends who you speak with because, what you saw change, certainly when I first started the emphasis on individuals diagnosed with schizophrenia has increased so there's no doubt that group has far more services than they did when I first started twenty years ago unless something's changed in the last couple of years. I can't see that happening though but for the vast majority of individuals, they've declined significantly so individuals, who may have been in the hospital diagnosed with schizophrenia, probably do have these services, wrap around services that are available for them, it depends who you talk to. They're probably going to be out of the hospital more often than not but I mean, to be fair, they may be getting as much contact with individuals outside the hospital as they had inside the hospital, there's a couple of nurses per shift, you know, so, maybe it's kind of a hospital, and I think some of these models are based on a hospital without walls, they provide the same services in the community. But these are very expensive resources, time intensive, human resource

> intensive services and the government is not going to throw a whole bunch of money at it. There is one pot and they focus it on that and there's a whole other big chunk of things that don't get money.

During our interview, in discussing treatment orders and personal responsibility, some issues I hadn't considered came up. Dave had clearly reflected much more on these things than I ever had, or perhaps, in experiencing the loss of a female client to suicide, I had become jaded about the protection that policies and boundaries were meant to provide. The central feature of this part of the conversation was about autonomy, or the place in therapy where the client or patient begins and the system and its policies end. That institutional abuses of authority are part of Canada's psychiatric history is not in doubt. The community mental health model represents a less visible enmeshment, ostensibly and relatively suddenly making people responsible for their own lives, after centuries of convincing arguments of the impossibility of social and personal harmony unaided by psychiatry. Here, Dave talks about community treatment orders or contracts that people make upon discharge from hospitalization.

> D: I don't think they have much of an impact. I really don't know how, I have limited knowledge of them when I worked in the mental health system and I really didn't seem them widely used or widely influential in people's lives. And it could be a particular situation someplace else but I think there's a lot of resources you need to be attached to those things to make them work. You need a fairly strong psychiatric involvement with individuals who buy into that, plus individuals who are able to have fairly sound conversations with individuals who have a treatment order on them, to agree and buy into this. So there's lots of things that need to be done that I don't think are easy to do. And then it comes down to underneath that is this idea of responsibility and that I really don't

know. We haven't made a decision about that, that boundary changes all the time. We really haven't looked at personal responsibility. And until we can start to be clear about what that means at least what we're going to accept in society, then, because there's one side that if you look at, say I murder somebody. And I'm psychotic when I murder somebody, I know there's going to be one extreme that says I wasn't responsible. It was my illness, and the other side will say you are responsible. And society will have these two camps, really and we haven't figured out what actually is for us as a group. And I think a treatment order kind of fits into that. You know what I mean. […]

And underneath it is this idea, it's pretty constant, is this idea that you can do the best you can but there's these other, people are responsible for themselves. And I've always found that difficult. Personally in my life, I'm fine with somebody suiciding. I'm not saying you should encourage it in people but I'm okay, to me that's their choice. It's not for me to judge that anymore. In my work I have to worry about that frequently enough. There's liability concerns that emanate through the work and I think if you speak with anybody who has experienced there's a certain conversation you could have to cover your butt. And then there's a helpful conversation which are very different conversations. And the helpful conversation probably will minimize the need to cover your butt too but there's so many things at play that actually force you to have that "cover your butt" conversations or do work that's not going to be the most helpful to somebody. That's one kind of challenge.

Dave's disclosure and revealing of the mental health system as he has experienced it resonates with the experiences of many of the other interview participants. Kelly and Layla are both partners and primary caregivers for women diagnosed with mental illnesses. Kelly also worked

as a residential counsellor and Layla worked as a primary addictions counsellor. Kelly, Layla, Collin, and Maggie are the intimate witnesses and sometimes reticent arbiters of the treatment orders that their loved ones have been sent home with. Kelly is the partner of a woman diagnosed with bi-polar disorder. In her occasional major depressive states, Kelly's partner has loss of reality and can become agitated and unwilling to follow Kelly's guidance. The police have been called to take Kelly's partner to the hospital. Layla is the long-time partner of a woman who has been diagnosed with schizophrenia. Layla believes the voices that her partner hears are those of her childhood abusers. The behaviours can be disruptive, as is the case with Collins' daughter, and they can be upsetting to witness, as is the case with Maggie's sister, Kelly's partner, and Layla's partner. When people insist that they are being poisoned, that others have spoken badly about them, that the world is a dangerous place, they naturally react defensively and in some cases dangerously. This is the reality for people living with someone for whom the world presents as hostile and unsafe.

5.3 Spaces of madness: Seeing and Saying

> "Well the question to some extent presupposes the answer; the question is already at least three quarters of the way down that road toward the answer" (Sean)

A broken leg has a structural reality to it, beyond the meaning that it holds for the unfortunate bearer of the broken leg—cancelled soccer games, inability to drive, potential ongoing pain. When there is talk of mental illness or madness, a whole set of unarticulated, unformulated possibilities comes into existence. Even yet, there is lack of consensus on how to talk about it. One the one hand, as Simon makes clear, just having a particular diagnosis, the very sound of it, is a signal to others, a ticket to trouble, perhaps. On the other hand, as Dave articulates so well, the change in the wind and the streaming of funds toward serious mental illnesses insists on the

very diagnosis for entry—no ticket, no talk. Inclusion in one realm, the medical realm, means the possibility of at least some exclusion from the other, social realm. Sally, Julie, Dave, Dannie, Mischa, Paddy and Sean are among the people who work to make sense of the language of the system. They are some of the people who work in the spaces and places of madness. In these excerpts, we hear from Sally and Julie. To begin, Sally describes her work in terms of policies and practices as well as specific institutions. Sally's experience and practice is situated in the 1970s and 1980s when she worked for community mental health services as a social worker with First Nations' families.

> Sally: We worked a lot with children who were in conflict with the law, and at that time it was prior to the current Youth Offenders Act. It was then the Juvenile Delinquent Act, so, kids who got in trouble with the law, we might do an assessment and it might have made a determination whether they would go to a correctional centre or training school or whether there was something else that should happen and we worked a lot with the child welfare policy as well and in conjunction with Children's Aid societies. Sometimes it was a CAS worker that needed more information or needed an assessment before they made decisions what to do with that child who was having problems at home. One of the difficulties was going out to a community for a day, seeing six to eight families and doing the assessment and then leaving the community again. So once a month we could do mental health treatment there, we could meet regularly, we were only out there for a month, once a month, and it was very clear we were doing assessments, not treatment. Within the communities which I mentioned earlier, there wasn't a lot of infrastructure for any kind of ongoing counseling, so I think that families and the schools and a lot of the agency people were left frustrated with the fact that we kind of came into town, did an

assessment, gave feedback and then we disappeared again. I didn't travel often because that was another coordinator's responsibility, but if somebody was on holidays I would go up and I was struck how poorly this traveling model fit there in particular. I wasn't sure that it was really, getting at issues in any of these communities in a substantive way, but the cross-cultural interactions that I saw between non-native professionals and the native people in the community, not only the clients and their families, but also the teachers in the school made me realize how poorly prepared we were in psychology, social work and other helping professions deal with the cross-cultural, with issues where the way people think and, the way people interact with each other is based on different values and beliefs so that there was, in my observation, a tendency for us to impose our values and our belief systems, rather than listening carefully to understand what people in the community were trying to tell us. For instance, one of the first situations I was sent to assess, it was a whole family system that showed up and the psychologist thought we should just do the family but I thought we should include everybody that came and that included a community elder and a grandmother and an auntie, and, a much broader perspective on how they could all express their concern about this child and the child's living situation and relationship with the school, but also the supports that could then be built in. And I wasn't very adept at it but intuitively it seemed to me that if a whole group of people showed up, it was because they were concerned and that we needed to deal with the whole group. In that case I got around the psychologist perspective by asking the parents of the child who they would like to include and that, from my perspective, anybody who was there was welcome, but it was up to them to decide. And they wanted everybody in, so, I welcomed everybody.

Sally's recollection of her work brings to light the treatment of mental illness or madness beyond the spaces of diagnosis. In this case, the whole community can be seen as the space where mental illness or madness begins. Incidents of mental illness or madness are not separated from the everyday life of the community. The first nation's communities that Sally visited as a social worker were not immune to the disruption of the community mental health model, but as Sally makes clear, there have been attempts to maintain a model of community balance, including everyone in treatment. The professionalization of services, though, does accord status to people designated from outside of the community as experts and this has at least the potential to create an internalized imbalance.

Sally described a model of community mental health services that attempted to be culturally aware and inclusive. In contrast is the prison system, where many people diagnosed with mental illness end up for a variety of reasons. Entry into the Sudbury Jail begins with surveillance and closed circuit cameras are everywhere. As a social worker in the prison system, Julie assesses prisoners and determines the next level of incarceration they will be processed through. In our interview, Julie also discussed her work in previous correctional institutions, some of which held people with NCR (not criminally responsible) designations.

Prior to the interview, I met with the volunteer coordinator with whom I had worked for several years as group facilitator. My meetings with the women in this context were always held upstairs, just inside the jail. On this occasion, the volunteer coordinator was going to give me a tour of the whole prison as context for my interview with one of the social workers. In one section, there was an isolation room comprised of four cells with steel doors and slots the size of mailbox slots from which the prisoners shouted and pleaded for someone to talk with them. I was not told of the specific reasons for segregation but during my later interview with Julie, the social

worker, it became clear that people with mental illness are especially singled out for abuse from other inmates as well as by staff. The designation of mental illness is a formalized process, as Julie explains, and is where people so diagnosed begin their journey through a blend of correctional and mental health services. Julie has worked in a number of mental health facilities and correctional institutes and her experiences encompass many years of working as a social worker.

> Julie: Many of those mental health policies where people were formed and were held by these forms. That would occur often. There were also policies that were difficult to actually maintain such as finding someone mentally unable and there's wording in there, to deal with, mentally incapable of deciding whether or not they wanted to take medication for their mental illness. That was very big. Whether they were mentally capable of making decisions in regard to their finances, and, in fact while I was working there, there were people who fought against, for the right not to take medication. I was very torn between both because, as a patient advocate, my main job was to, it was directed, I got directed from the client and I was supposed to help him and, as a social worker, I really thought, especially in some of these cases where they were not, they didn't take medication, and were not made to and were found to be mentally capable of making that decision. Boy, I had difficulty seeing that they were mentally capable, to be quite honest, because some of these people had spent their, twenty, thirty years in some institution or facility and will never ever get out. Many of them, they weren't in for murder, but because of their severe mental illness they were held and they would go, you know, what was it you were saying, ah, policies. Every year they had the right to appear in front of the Ontario Review Board and sometimes, you know, it was a very difficult

> thing for many of them because they had such severe mental illness that was left untreated often, you know. So yeah, I'm still, to tell you the truth the jury is still out for me, whether it's the right thing to do because, in my mind, they were not capable of making good sound healthy decisions for themselves.

In the next excerpts, we hear again from Dave, from another space. Dave describes the ineffable quality of a psychiatric waiting room. Having been there myself, many times, with both clients and friends, I think he is right—there is a different tone to this kind of waiting. Perhaps the tone is a distant vibration of past episodes that have resulted in this very scene, sitting in this very chair. Common to the experience of the limit experiences of intense fear, or anxiety, or intense despair, or depression is the anticipation and avoidance of ever feeling that awful thing again. The irony is that both anticipation and avoidance are precisely discordant with the harmony and balance that Tim speaks of. Indeed, thoughts about the future and past, dread about the experiences of the mind and monitoring as avoidance are commonly known to exacerbate fear and despair.

Dave discusses something similar to but perhaps more insidious and personal than stigma. The waiting that comes with a mental illness diagnosis becomes a place of memories and expectations. As Dave discusses in this last excerpt, even though there is generally a wider acceptance of what is called mental illness, and the chronicity and length of hospitalization is not as dauntingly interminable, there remains something quantitatively different about a mental illness diagnosis. The difference between a mental illness diagnosis and a physical injury is perhaps connected to a subtle fear of catching mental illness or madness; combined with messages about self-monitoring, this becomes a condition of hyper vigilance.

Dave: I know the diagnosis but see I'm sure if I watch a cartoon for Prozac or Paxil or whatever you'd think, "Oh, maybe I've got this". Like everybody's got symptoms occasionally so it's causing at least everybody to think that maybe they are, right? And before it was clearly you weren't. You were something very weird if you had that. Plus they had people institutionalized forever too though. I mean it was really like, if you went to a psychiatric hospital, it's a big chance you're going to be there for a long time. Now if you have a psychotic break, you might be out in a few days. If you get in. It's not the same thing, certainly there's no nervous breakdown, there's no chronic institutionalization. There's a kind of, a flavor of contagion to somebody with mental illness. I think that's changing and I think that's more because in some ways mental illness becomes a bit in vogue unfortunately. But that does have a positive effect. Anybody can be depressed, there's cartoons about it now, so that's changing. I don't think it's changed totally. And I think that probably will change. I don't know if the idea that it's going to be more of the same thing. There's a resignation to that too in some ways that there's a mental illness and it exists and here it is. It kind of rallies around it and becomes part of life and different industries perpetuate it. The pharmaceutical industry and all the other industries attached to it, they've established themselves. It's pretty hard to change that. Except for these big law suits against pharmaceutical companies for whatever sort of.

M: I like the way you put it, that flavor of contagion, there's something a little bit different about that waiting room. Different than if you go to the regular waiting room where people are

D: Actually contagious

M: Yeah, it's so strange

D: Yeah, Stumble into one by mistake. How long would it take you to realize it? I could talk about a lot of this stuff and a lot of this stuff is not clear in my mind too so it kind of emerges conversation-like about certain things. Like I think the mental health, personally speaking, the mental health system has a lot of potential. I think that was one of the most enervating things about the work was that increasingly people kind of were resigned to the fact. Like you're seeing people resigned to where they were. There wasn't a lot of hope that they would do better, just stay out of the hospital. I'm not there now, so I imagine it must be very difficult. And not to say it's worth complaining about, this is the work that they do, but probably underneath it, it's a difficult thing to do daily, to feel inspired and just to keep somebody in a palliative ward. But you see people have a lot of hope, they go to school, they're moving forward, so there's hope.

Dannie, a psychiatric nurse, has also worked in clinical settings such as hospitals as well as through community mental health agencies. Here she describes different ways of seeing madness or mental illness and, like Dave, she discusses the place of media in making talk about mental illness more common and less isolated.

Dannie: I was lucky I worked at inpatient, it was exciting, hospital was a forerunner, we were up to par with hospitals in TO. I moved into addictions and they were very dynamic and most addictions had mental health. We were using narrative and teaching skills, role playing, relaxation, stages of change, family and marital, cognitive and behavioural therapies but there isn't a lot of prevention and there's not a lot for families. Dr. Oz and Phil Donahue de-mystified it.

M: Can you say more about that, demystifying

D: Like the cancer society, people want to come back and help. With mental illness, it's like the stigma, once you're well, you don't want to come back. If I listen to someone else's story it might pull me down

Dannie points to another subtlety of insider mad or mental illness talk. She has noticed this from her experience of listening to clients or patients describe their experiences of the phenomenon. In noting that people, in her experience, tend to avoid others out of fear of being pulled down, she gestures toward one of the places of madness. That listening to someone has the possibility of bringing someone down is an interesting feature of mental illness, the ideal psychic location perhaps being somewhere in the middle. So madness does have an architecture, a psychic structure. One cannot just *be* mad under these conditions; one must be on the way to another psychic location, up or down. Through listening to people describe the motivations for avoiding a situation or person, Dannie has brought to the forefront descriptions far wider and deeper than a diagnosis can provide. That the internal and under the skin experiences of madness have a rich and meaningful logic invites more mad narratives, beyond those that take place in clinics and waiting rooms.

In the next excerpts Mischa and Sean discuss the use and limits of language. First, Mischa describes a round table clinical interdisciplinary dialogue between colleagues. Sean steps back from his practice to critically analyze the language of diagnosis. Mischa and Sean are both social workers and each interview took place in their respective private offices. Mischa discusses a different environment and for her, environment is everything. What is most significant about Mischa's descriptions of her work is the attention to context she provides.

Mischa: The work is defined by the environment you're in. In terms of colleagues it's really interesting to work in a multi D team. It's really interesting to listen to your

colleagues and listen to what your colleagues will bring to the table and it can be very powerful in terms of understanding the patient. Here (another setting) we work independently and we may not see eye to eye but with the clients we try to pull together.

M: What do other people say about the kind of work you do?

Mischa: There's a lot of joking around the work I do like you're in psychology because you have your own problems but people turn to me for not necessarily advice or guidance and that's kind of tough a lot of it is cultural in the sense that we often deal with the unknown it's not an easy thing to open up and share your intimate stories and so people then a healthy way of managing that is to joke about it. Television shows tend to portray people with mental illness and those working in the field in a certain way. I think that's one of the negatives is there is a lot of stigma even if you look at the media the people the new mental health commission is going to teach the media how to talk about mental illness and because we don't talk about that as a culture we don't talk about, we talk about physical health and it mental health falls behind it

Both Dave and Sean come out of an era of creative therapies, broadly on the heels of the therapist centered period previously discussed. What is clear in their rich analysis of the terms used to describe madness and mental illness and in the experiential wisdom of their respective approaches is that each has cultivated a philosophy of therapy beyond the manual modes in which they were trained. By the time they were asked the questions for the interview, they had clearly been reflecting on the issues for many years. Sean has worked in many settings under the rubric of psychiatry and mental health services. As well, Sean's experiences substantiate and concur with the system as it is described by those accessing services. What Sean describes is a

type of currency, expressed in the language of diagnosis, the language of the DSM. Without a diagnosis, people cannot get services but with the diagnosis, and subsequent protocol of various treatments, comes a prognosis.

Moira: Can you describe your work in the field of mental health

Sean: The name that I would, or title that I would identify most changed over the years, often I would be social worker or clinical social worker depending on who the employer was how they made these distinctions. For a good part of my career I identified with psychotherapy and saw myself as a psychotherapist until [laughs] the government of Ontario decided that psychotherapy exists, there are psychotherapists and since they created a college of psychotherapists I'm less interested in being one and now I'm a counselor.

M: Can you say more about that?

S: Psychotherapy has a word origin that goes back to medicine, so psychotherapists were trained in the dynamic therapies and other types of mental health practitioners would rally around different titles identifying with their own discipline, psychologists would call themselves psychologists and psychiatrists would call themselves psychiatrists, social workers, nurses, other who worked in the mental health field tended to go by that title and some were interested in what was the function of the work, the work itself and not so much the credentials that allowed you to do the work.

M: Can you say a bit more about how that came to be?

S: Some of it was coincidental in my own evolution as a practitioner and as a person to some extent coincided with legislators deciding that this kind of work ought to be

> organized and through college and formal titles assigned to persons who practiced this type of work and they could access these titles with certain credentials and they would name professionals that could have legitimate claim to these titles own profession is one of the named professions that can lay claim to psychotherapy or psychodynamic therapy while that was happening my own views were crystallizing around a non-medical approach to the work and that had been the case for me for a long time but coincidentally at the time that legislation was being organized I really just evolved entirely through all those sort of associations with medical practice and DSM based practice.

Sean describes how he used the terms sanctioned by the DSM as a way in to the system. He knew that certain diagnostic criteria had to be met in order for someone to walk through his door, but once in, the system had served its purpose and he could continue in a manner less bound by treatment modalities. Sean and others who had many years of experience described policy changes that occurred in the late 1970s. Sean, Dave and myself would have all been beginning work no more than a decade later so I was somewhat familiar with the practices and therapeutic culture that had been present. Although we did not work together, many of our supervisors would have been influenced by the policy changes to which Sean referred during the interview.

> M: Okay, that's really helpful. Can you talk about policy, the influence of policy decisions on you carrying out your work?

> S: When you talk about policy I hear the word kind of manifesting itself at two levels—at legislation and at the level of the workplace in the form of organizational policies, that sort of thing but if you were to add to that definition of policy the culture of the practice, then I think back in the 70s which pre-dates my direct involvement with any of this when

the DSM went from being organized around basically psychoses and neuroses to the current five axis system, that's when the medicalization of mental health issues really kicked in in earnest and it brought about the not so gradual reification of these ways of classifying things that people would report about themselves. What it did do over time was it become increasingly reliable over time so sorts of things that mental health professionals would determine about folks as they came in and described their problems would be consistently done across professionals there was reliability in other words but it really didn't add up to a whole lot and there's nothing in that book the DSM that speaks to treatment, nothing whatsoever, nonetheless the things that are described there became accepted in the broader culture as real things and so when for example a person gets a diagnosis of this thing or that thing they actually believe this thing exists that it is real and it almost has a life apart from them, it's just it's something they've contracted the way you might, like a virus or something so the meaning that people attach to this thing really kind of informs the possibility and limits the possibilities at the same time, it just orients everybody in a certain direction— the person providing the service based on the identification of a certain problem and the person receiving the service who has now a fairly narrowly defined set of possibilities as to what's going on and what can be done about it and so on

M: What would you say are some of the challenges of your work then?

S: If you mean what's it like to work in the mainstream system that's basically premised on the truth of the DSM, when that same individual doesn't hold that literature to have the same meaning. It creates I suppose an underground conversation with like-minded colleagues for one thing, there's probably a disconnect between formal reporting and

> informal reporting I might be obliged and have been at times in my career to report to the system using formal accepted language, which is language of the DSM so clinical notes might require some comment on diagnosis and a formulation that has something to do with that and a treatment plan that has something to do with that and certainly it would require some awareness of what would be thought to be so called best practice and best practice would almost always have something to do with the DSM at least as a point of origin so for example how does one best treat a mood disorder, anxiety for example, generalized anxiety just by way of example, well the question to some extent presupposes the answer, the question is already at least three quarters of the way down that road toward the answer because I wouldn't pose that question I don't really have any interest in that question. I don't think talking about anxiety is a terribly useful thing to do even for people who report the experience that is called anxiety.

One of the challenges that Sean discusses is in people's expectations when they come to see him. Because we are inundated with messages about serious mental illness, social anxiety and other mental illnesses, this is what people expect to discuss when they come to see a mental health professional. Despite Sean's and Valenstein's accounts of the lack of solid evidence for these diagnoses, people come in wanting a solution to these conditions, believing them to be similar to other illnesses.

> S: So the challenge, is or one of the challenges or another challenge is that people come in with, typically anyway, some awareness of not so much the DSM by name but its contents, they've certainly heard terms like anxiety depression, it might be something more specific, whether they've seen a mental health professional previously or not they're aware of these terms. they have seen a mental health professional before,

> especially if that mental health professional happens to be a psychologist or a psychiatrist, they come in with certain set of expectations they think that's how the work is done that's how it's organized it's not a major complication but it can be a factor in the early going that you're having to make individuals understand that your orientation to the work is not the usual deal, you don't tend to do the work from that kind of conventional or even orthodox orientation so that can create a bit of dissonance with clients so that might require a conversation around that sometimes it means additional work at establishing not just rapport which is something that is always required but credibility. I might have do the dance for a little bit so the individual can understand that I understand and then move the conversation in another direction with of course the consent of the client but after you've sort of spoken to what the possibilities are so this goes in a very authentic way to informed consent. So often what I offer is at variance at what they expect based on what they've been told from many different sources.

Sean's story provides an inside analytical perspective of the ways madness and mental health can be talked about. This is connected to ways of seeing madness, and as Sean make clear, the mental health system and many of its delivery channels rely on the language of the DSM. In particular Sean's reflection of the diagnostic process wherein a person diagnosed with schizophrenia is a point of contact for many of the interview participants. Although not a measurable entity, as Sean points out, people go away with, for Maggie, a word she cannot bring herself to say in reference to her sister; for Simon a word with a hard "k" that will impact his personality in the long run.

5.4 Remembering the Past

Psychiatry was once the specialization of relatively few; ideologically and practically it was dominated by men of science and reason throughout the nineteenth and most of the twentieth century. This perspective left little room for mysticism, dreams and approaches to madness that we have come to know as wisdom traditions. Jungian analysis and Freudian analysis exploded into mainstream popular culture in the later part of the twentieth century, the former encouraging the exploration of dreams, symbolism and archetypes and the latter tearing apart the rooms of the psyche and populating them with Greek mythology. Pop culture Guru Timothy Leary and literary mystic Carlos Castaneda encouraged LSD induced mind expansion and dreaming, and shamanism respectively. The beat of another drum was heard in the militarism and justified mind control experiments of the Cold War, described by Anne Collins' accounts of the psychic driving experiments of Dr. Ewen Cameron (*The Sleep Room*).

Jack, a psychiatrist, had been trained in the 1940s and 1950s climate of experiment and suspicion. Due to his illness, I saw Jack on three different occasions. Jack matter-of-factly recounted some of the general philosophies and treatments that he was trained in. Much of Jack's work took place in Sudbury and he was one of the few people who could recall a period of time when people were sent by train, in shackles, to psychiatric hospitals outside of the city. The interview centres on Jack's recollection and memories of his training and career as a post-World War Two psychiatrist. Jack's candid, uncensored reflections are his own reflections but they do reveal the separate spaces where mad or mentally ill people were, and often still are, said to belong. Jack's story highlights the surveillance and suspicion which formed the psychiatric gaze in this era.

M: Can you tell me a bit about your experiences working in the mental health system, in the time you were there?

J: Well, I only recently retired. But the Mental Health Act is very recent and that allowed people with mental illness to be held in a hospital. And in Sudbury, if you became psychotic, you could be held in a hospital until such times as you were no longer a danger to yourself or the community. In the early days in the last century, if you became psychotic, you were certified by a doctor, not a psychiatrist or doctor and shipped off by train to Toronto to Queen Street handcuffed.

M: In the 1950s?

J: In the 1950s. But before that it was catch as catch can. Nothing was formally arranged. Occasionally people with a mental illness ended up in jail anyway. There was no formal arrangement to get them in there.

M: So what would constitute mental illness? How would that happen?

J: Somebody who was in a state, or somebody whose behavior was such that they were a danger to themselves or other people. There are many psychotic disorders now, almost any of them, hallucinations and delusions, would lead to certification. And before 1950, he would end up in jail or in Toronto. You'd be handcuffed on the train directly from Sudbury to Toronto on the train. There was no road from Sudbury to Toronto; there was a road from Sudbury through and down Highway 11. Hwy 69 wasn't there so they went to Toronto by train. As soon as they were a danger to themselves the procedure was initiated and that would be the Mental Health Act before in Ontario, but mostly it consists of jailing lunatics based on irrational behavior. They were a danger to themselves or somebody else but we got away from the idea of lunatics, the word or the term lunatic,

they used to believe that when the moon was full, that's where lunatic came from but it's not true. It wasn't until 1950 when the Mental Health Act in Ontario was the first province to have one, and each province had its own Act, but they still put people in jail when they were mentally ill so that was the state of affairs until 1960. Also coincidentally TB was a rampant disease in Ontario certainly until the middle 50s and most of the time people stayed in a TB sanatorium for about two years and the nearest TB center was in Toronto. So if somebody got diagnosed with TB, they were shipped off to Toronto or to the States for a long drawn out two years or so. With isolation of fresh air and good food, it was supposed to cure TB when it occurred and in fact it didn't. It may have caused the disease to remit and they seem to be cured but they were still infected and they gave the disease to other people. As well as being away from home for two years because there were no institutions to deal with either people with TB or the mentally ill. And it seemed to be cruelty, the isolation breaking the families and all the rest of this applied to the TB act and the Mental Health Act. But the TB, for a different reason, but they were a danger to others and of course to themselves, of course. If you were danger to yourself from a mental disorder there were similar kind of ideas in any case, you should be set apart. The Sudbury hospital, that’s its real name, it’s not called that now. Sudbury and area raised money for a TB hospital. It’s easy to get money for a known illness, and at that time it was built to the budget, and the builders came in ten cents under the budget, it was a publicity stunt. It came into use in 1962.

M: Can you say more about that, how the money was found?

J: In two years or less of the hospital being used as a TB hospital TB was finally cured unlike many of the infectious diseases. So the hospital was built by public perception

mostly and then people with mental illness were the next to fill those. The only form of mental illness that they knew for certain what caused it was schizophrenia, and the result from a positive syphilis test. Originally that was the only mental illness they know the cause of it rapidly spread. That idea became that mental illness was caused by sin, disease or poverty. Sin, disease or poverty definitely help, but they are not the only causes of mental illness. Sin being people believed if you had syphilis, you automatically had schizophrenia, or if you had schizophrenia, you automatically had syphilis, but that's not true either. It was a common belief there was a moral prejudice right from earliest time certainly from the fourteenth or fifteenth centuries when bedlams were opened; there was a hospital called bedlam that was where people were placed. They were open to visits and taunting from the various public that came in and they were chained. But lots of people believed this, really believed it.

M: In what capacity did you work in the mental health system? What was that like?

J: I was an orderly, a medical student in England. Four days on four days off. So I swapped my days around so that I mostly worked evenings and nights. So the first two years I was also an orderly in the psychiatric ward. It was the only job that I could go to my classes when I worked as an orderly. There were only two treatments: shock and barbiturates or sleeping medication and nothing else. This was in 1960. The earliest one was Largactyl, a powerful anti-psychotic. Before that people were held down by force and given shock treatment to alleviate the mental illness. The origin of the electric shock treatment goes back some. There was a superintendent of the state psychiatric hospital, a big two thousand patients, it covered the whole area. It was in international journals, it was almost knocked down in its infancy. And he noticed that people with epilepsy didn't

> get schizophrenia. That's now true it happens, you get some with schizophrenia. Shock treatment wasn't an issue initially; it was done by chemical injections in order to cause convulsions in the beginning. We're talking about 30 or 40 shock treatments a week, and they were not zombies that people made out. We'd try it for two or three months.
>
> M: So when you came to Canada you worked in the hospital and in the prison?
>
> J: I did two years, and then I joined the Air Force and I got transferred to the psychiatric hospital. So I did my training in the Royal Air Force late 40s or 50s. It was quite good. You saw a lot of people who were frankly psychotic in the lunatic asylum, acutely psychotic, all you had was shock treatment. It improved the ones who had schizophrenia. People who were psychotic from street drugs were a major problem where, in Vietnam, most of the men used cocaine, LSD, pot to withstand the rigours of combat. By and large you also quite a lot of people with psychosis, schizophrenia, bipolar. As a result of this…and the Air Force was quite avant garde and picked up new treatments.

Jack's story makes visible some of the theories about mental illness that he describes as "still floating about". He opens a window onto one of the more dangerous features of psychiatric medicine—that of its practice of combining *theories* about particular conditions with actual *practices* such as the introduction into the treatment protocol of psychotropic and electro-convulsive therapies. Paddy's experiences in the mental health system come quite a bit later. Jack's and Paddy's experiences are separated by only a couple of decades. Paddy has worked in a clinical setting for most of his career. He discusses the limits and possibilities of community mental health services. What becomes apparent in an analysis of a few of Paddy's statements are the ways in which people, formerly described as patients, when seen in the community are

regarded as having needs that are community based, such as socialization opportunities. Paddy makes note also of the tether to the legal binds of diagnosis.

> Moira: Can you describe your work in the field of mental health?
>
> Paddy: Psychiatry has changed over the years actually. How it is perceived over the years, it's also a social perception about the mental illness that has changed immensely, but at the same time some of the laws which govern the psychiatry and mental health have remained—the older ones, though the thinking has changed and it has become much more acceptable with more voluntariness of involvement of the people. We still have the older generation of mental health acts, so that needs to be changed. Originally the mental health act pertained to psychiatric institutes—they were in the mental hospital or asylum setting or in institutions where they were commitment and eventually released.

Paddy entered the mental health system as a psychiatrist around the late 1970s. He describes the tethering of the present mental health system to the asylum era, an era which seems in Paddy's description to extend into the present. Just as Mischa in the previous section described the "complexity" with which mental illness is seen and described in a clinical setting, Paddy notes that psychiatrists have to assess the needs of those they see from a legal and a social standpoint.

> Paddy: This stigma of some of the treatments say, for example, electroconvulsive therapy, had been a major issue when I was working in the USA. So many people have not had access to electroconvulsive therapy, which has actually 90% chances of improvement in real depressive disorders as compared to the medication, which is still having an effect of maximum efficacy of up to much less. We are the major leading center for ECT. Activity centres social organizations and clubs must be available to these clients, which is another thing that I'm looking at. There are valid psychotherapeutic

interventions there but they are not accessible but easily, because of lack of trained personnel, number one; and number two, because I've been in northern Ontario here and not many clinicians are available to really deliver something like CBT. It is a big issue.

M: What are the main challenges that you face in your work?

P: It's still a stigma. I think psychiatry is still not accepted in the mainstream as a medical specialty. Psychiatry is always looked upon as a special set of the system and so there has always been a disadvantage in that way and even the psychiatric patients are also marginalized to a certain extent. There is still a stigma that is present even today, so both from the patient perspective and professional perspective, there is still hurdles there and that way. Number one is the fear of the unknown, almost like you don't know what the next one to expect there. And it is quite understandable in a sense. Some of the mental illness disorders are quite unpredictable in their impulsivity, so mood disorders, or one and paranoid psychotic disorders are the other ones, these two are still very, very, scary rather, even for the common public and even to the family members too. They must be on their guard and watchful all the time. As the years pass they come to know some signs and know how the behavior usually triggers something else. What are the precursors? Are certain aggressive behaviours the people closer to them would be able to identify? So that impulsivity and lack of judgment is still a major issue for mental illness and, half of the time, I think it is quite a realistic fear of the common people.

M: Similar question here, there are only two questions left, what do people seem to think cause mental illness in your experience? You are saying that there is the unknown but do you think we think we know how someone with, say, bi-polar, is going to act, so we kind of and they kind of, expect that?

P: There is a mixture of two cultures here, primarily the native culture and also the European culture that is a part of Canada. Somehow, as the generations have passed, no medical model of thinking is okay, or says it all, with the European culture be seen to be quite understanding about it as an illness; but from the native culture wise, I think it is still unacceptable as an illness. There are still a certain amount of natural changes that are the cause of the behaviours which are still a part of the thinking. It is difficult to engage a person with the native culture to a certain extent as not everyone to believe system is different that will really affect their ability to perceive it as an illness and seek treatment, and or accept [it] as an illness that needs to be treated so that I still see in this community.

M: Were there differences or are there differences in the way that people with physical illnesses and mental illnesses are treated generally?

P: Yes, there are differences still. That is the point still made. Same person, we are still having the stigma in the emergency rooms now, a person with a heart attack, even if he has a label of schizophrenia, comes into the emergency room, he is first a mental illness rather than heart attack problem. So that is why there is still that stigma that is there, even in that situation even in the emergency room. So I think, unfortunately, it still present physical illness can happen even in a mental illness patient. So you should still be open to the aspect of physical illness first because that is more emergency thing, an issue that they present with an emergency room. And I think at the community level, I think the difference comes with the update the additional amount of time that has to be spent on a mental illness patient. Because of today's, unfortunately mental illness is also misused by the public, there is a certain amount of the misuse of the label of mental illness to explain some behaviour, which is probably not due to mental illness. So because of that

physician, why's there is a reluctance to really accept the care of the patient with a mental illness or with mental symptoms. So accessibility could be a problem. And another thing is to help with their social issues; even though he is a real schizophrenic patient, he may not get the complete help, like the social needs, like a disability or financial supports, housing supports. So is time-consuming. It needs a lot of effort from time point of view, from the family physician, so therefore they are reluctant to spend that extra amount of time. So there's a difference how they can handle that, so that is one thing that I have seen.

5.5 Summary

The mental health movement would have us believe that at least one in five of us has some form of serious mental illness; if we do not have one now, then we will have it in the future. We are bombarded with messages to talk about mental illness but not madness, to watch for early signs of distress and to seek professional help at any signs of distress, and increasingly at any signs of discomfort. The war on drugs has become a war on mental illness and madness, a rationalized and legitimized approach at management and self-surveillance quite beyond what asylum walls could ever hope to achieve. This chapter heard voices from inside the places and spaces of madness from people who have been there and worked there. The critical perspective of the use of language to narrow human experiences, the shutting out of traditional approaches, the esteem and status of clinicians, and the power of the extended psychiatric system, psychiatry’s attachment to psychological warfare and social experimentation interrupt the sane and hygienic figure otherwise presented. Mad people are talking too. They claim that room should be made for madness and other ways of describing mental illness.

The excerpts in this chapter were drawn from the actual day to day work practices, reflections, beliefs and tensions that people engaged in the delivery of services experience. I was surprised during the interviews at the critical reflection that many of the workers revealed. I encountered true believers, people who did not offer any critical analysis of the mental health system in only a few of the interviews. These less critical perspectives were from those most closely aligned with the medical system—psychiatrists and those psychologists who worked on multi-disciplinary teams of mental health professionals. Workers and care-givers in colleges, prisons, homes, private practice, churches, holistic traditions and schools revealed ways of navigating with and through the mental health system that often defined who they could see and toward what end. During the interviews, they reflected on the questions, seeming to be truly interested and passionate about the constraints and contradictions within the system. They were often more critical than those accessing services yet they described providing services within the framework that the client, consumer, or prisoner was accessing and under the expectations therein. This struck me as incredibly skillful. The mental health system was being worked from within by some of the more creative of these people as they responded to each case with a unique approach, sometimes leaving aside best practice modalities in pursuit of genuine relationship with the people who had come, or had been sent, to see them.

Chapter Six: Discussion

The thesis began with the silent asylum era. From this point of view, Langmuir described the asylum as he saw it as part of the larger structure of the asylum system. This system included a lucrative hiring out program and the exploitation of patient labour. Reaume's work is most notable in Canada in this regard. By the mid-twentieth century, psychotropic medications and community mental health services facilitated the evacuation of many people from institutions. Angry, hurt and mad voices joined with other civil rights activists to launch a critique of the psychiatric system. Mad voices were heard but often dismissed as paranoid, conspiring, emotional and unreasonable. In the later twentieth century a softer, gentler mad voice could be heard as that of the reasonable consumer. This thesis contributes a balance of voices; it is neither a chorus nor a solo. The literature about experiences of mental illness and madness has been advanced through this work by the people who agreed to participate in ethnographic interviews. They agreed to participate in a critical ethnographic study as part of a social historical analysis of the mental health system. I have invoked their collective voices as mad voices and challenged their identities as informed consumers.

The primary voices in this thesis are those from inside the mental health system. These are the voices that offer a univocal challenge to medical authorities such as John Langmuir, Joseph Workman Burgess, Bryce. Langmuir, Burgess and Bryce were men who hoped to make history and they did, changing the way mental illness and madness were seen for the end of the nineteenth century and the better part of the twentieth century. A groundswell of voices of experts, psychiatrists and television therapists dominated the post WW2 era as Canada, along with other Western countries complied with the relative peace and victory of traditional values,

rigid gender roles, and the indulgence of self-analysis. Talk therapy has been a lucrative industry since it emerged. Professionalized voices continue to speak for mad and mentally ill people within and outside of clinical services and hospitals. What is at stake and what is challenged in this thesis is the claim of psychiatry to claim exclusive authorship of mental illness and mental wellness, at the expense of the existential limit experiences and facets of essential humanness. What is offered in this thesis is a pause in the authoritative voice of diagnosis so that some voices of those who have been most embedded in the psychiatric and mental health industry can be listened to.

I am not nostalgic for the madness of the time before reason. This time, for me, was the 1980s when in mental health, anything went. This was an encounter of a different kind, when the green asylum walls burst open to reveal not their mad, but their madness. Of course, Foucault has said this. Beyond Foucault, just out in the parking lot, really, a new asylum was built. There are distinct periods in this thesis. Throughout, I have been aware of the appearance and absence of the mad person. That the state of madness has recently been enfolded back into its other two companions, addiction and crime, presents an interesting question for the study of the experiences of madness.

The underlying theory of the thesis—that the present psychiatric and mental health system is tethered to organizational networks and that it represents in the present a particularly authoritative voice in contrast to other voices—is supported by analyses of the interviews. People were willing and eager to talk in a mutually created exchange of knowledge about their experiences working in or accessing services within a mental health system in Sudbury, Ontario. Bloggers, such as those engaged with the blog site “Mad in America: Science, Psychiatry and

Community" as well as contributors to *Phoenix Rising: The Voice of the Psychiatrized* present voices from another perspective.

My first encounters with madness came through imagination. Like many people, I have been exposed to madness all my life. It has come closer to me at times, at times even getting under my skin for a while. From Lewis Carrol's Hatter, always in trouble with authority of some description, upsetting and troubling the everyday, condemned in perpetuity for murdering time to the more immediate signs of something gone wrong, something kept away and apart, perhaps for murdering reason, this latter being the mentally handicapped children behind the brick wall of a Glasgow institution, an institution my uncle had founded and which I was taken to visit from time to time. These are the shapes, images, shadows of madness to which I was exposed. Later, in my work in a genuine asylum, I came closer to something I thought might be madness as the elevator I was on stopped to let me witness an assemblage of naked bodies waiting to be showered; their caretakers sat at a nearby table killing time and chatting over coffee. Madness was in the primary colours of a childhood story and in the lime green walls of various institutions. With the promise of one came the threat of the other. Much later, my interest in the social organization of people through the mental health system could not help but be coloured with the richness of this experience. Others have had similar interests and it was this shared compassion for those crippled by the psychiatric and mental health industry that enlivened the ethnographic interviews. These were people who were also genuinely interested in how madness and mental illness are seen, experienced and acted upon.

The thesis drew upon three primary areas of evidence: (1) social historical data, (2) first person interviews with 30 people involved in the mental health industry, and (3) reflections on my own experiences of front line mental health work, primarily throughout the mid- to late

1980s and the 1990s. This complementarity of sources has provided a focus on a critical read of the social historical organization of mental illness in Ontario. For example, the thesis demonstrates a pivotal era in psychiatric history is the move outward from institutions and into community mental health care. R.D. Laing, in *Going Crazy* launches harsh criticism of psychoanalysts, psychiatrists and therapists:

> What have they actually been doing for the last half century? By and large they've been power-hungry, money-grubbing apologists for the existing order. Male chauvinists and bourgeois rationalists who have lacked all respect for the awesome depth and complexity of the human experience. Better to have used butcher knives on their passive patients' aching minds… (Preface)

As well as adding to what is known about the phenomenon of being in the contemporary mental health system and what is known about the historical social organization of Ontario's psychiatric system the thesis continues to counter psychiatric discourse with multiple voices of being, before, after and without a mental health diagnosis and to make visible the flow of techniques, practices and discourses of psychiatry over time. The thesis makes clear that people describe and self-describe in their own terms, outside of the language that courses from the top. Christopher, Quinn and Jane discussed a type of currency involved in getting into the doctor's office. The exchange is described as being surrounded and organized through language. There is discussion of the inadequacy of language—especially medical language— to describe properly their experiences. The social organization of mental illness has changed. Former patients are now ostensibly informed consumers or peers. The autonomy that was promised by this marketing term is illusory. Women are still bribed into taking methadone and other treatments with the promise of being reunited with their children. People are often not properly instructed in the long

term effects of heavy sedatives and medications that are offered as the only solution to increasingly frightening depictions of mental illness. The people interviewed in this thesis describe these contradictions with more or less knowledge of the long term effects of psychiatric products and more or less awareness of what it is that their families, co-workers and friends expect of them. The analysis of these reflections and of the mental health system is the ongoing. The system has evolved from a social movement of mental hygiene to a lucrative industry. I have described the present mental health system as a burgeoning economic force that seeks to turn more human experiences into pathological units of correction and rehabilitation. It is within the micro practices and strategies as defined and described herein that change can occur.

The main themes that emerged from a reflection on the social history and ethnographic experiences are those of ways of seeing, living carefully, repression and relief, making meaning, cures and treatments and waiting rooms, spaces of madness as well as remembering the past. Some of these are connected to historical projections of madness, how it came to be regarded and treated and, how it came to be feared, how this opened up the opportunity for legal recourse to imprison people. The social history included a description of the practices and policies that created the institutional system.

The new forms and shapes of madness which this thesis brings to the forefront can thrive only in the new mental health context. Mental illness and madness, the way that these are experienced and understood by the participants and contributors to this thesis through interviews, risk alienation at best and extinction at worst as they are no longer needed to sustain the newest models of mental health services. As many of the interview participants have described, visits with psychiatrists are not as fruitful as the mental health industry claim them to be, partly because of a disjuncture in expression and ideas of what it means to be mad. That this is

happening in an era of particularly sharp theoretical discussion of what it means to be human is all the more intriguing and alarming.

The contribution to the literature that this thesis provides is in the fruitfulness of ethnographic work which reveals hidden and private worlds of negotiation through the currency of language, various forms of disseminated, involuntary incarceration and other forms of power enacted on the body to name just a few manifestations of personal, legal and political power as discussed by the caregivers, service providers, survivors and consumers. That these forms of currency are flowing within a lucrative and profitable psychiatric industry is cause for continued exploration. Through the interviews, participants' awareness and reflection on their experiences can be extended for useful critical analyses of what it means to be human in increasingly restrained and constrained social contexts. The people interviewed discussed and reflected upon what the mental health system is and does for them, the techniques and strategies they use for making use of it while mitigating its power to define the limits of human experience. Although some of the experiences people describe have been painful for them, what they offer is the possibility of transcending rigid boundaries of normalcy that constrain more and more human range. Collin speaks honestly—this is not what he wanted for his daughter—but here it is. What are the risks that Collin has been taught to look for? Cassie knows fully and deeply that something is missing. At some point she may find the dangerous green boots back on her feet or they may remain in the closet.

These are the pasts and presents and futures that were shared in this thesis. The mental illness and mental health system, through its powerful discourse, has come to surround and permeate all areas of life. The contemporary mental health *consumer* is ubiquitous and hard to define as more and more of us can be swept into a future oriented prognosis of increasing mental

illness. Psychiatric survivors represent a political identity aligned more or less, with active resistance to the mental illness and mental health system and with the practices of psychiatry. As Sean makes clear, the system is so tightly tethered to how people view themselves post-diagnosis that it is hard to untangle oneself from it, despite all the talk meant to reduce stigma. Sean says, "..so when your basic point of reference is 'let's reduce the stigma about these things', these things are still a huge part of the point of reference that the stigma flows from or attaches to" (Sean).

The social phenomena of heightened surveillance and subsequent self-surveillance is particularly difficult for mad people and people with mental health diagnoses. As described by many of the interview participants, there are many protocols and processes through which one must enter to get into the mental health system; that there is no clear exit from the system and no formal end of treatment is indicative of one of the many ways in which mental illness is experienced very differently than other illnesses. Mad people are governed quite differently from their not mad counterparts. Outside of the hospital system, mediated and aestheticized ways of being mad are represented in campaigns meant to normalize madness, sterilized by the term mental illness. Concurrently, people describe shame and being shamed, an issue that mad activism and organizations such as Toronto's Mad Pride seek to redress. In the context of public and private social institutions, such as hospitals and universities, institutions which are seeing increased surveillance and regulatory forms of management, behaviour is carefully monitored and negatively sanctioned.

Felix Leclerc, in *The Madman, the Kite and the Island,* tells the story of a man who washes up to shore claiming to have lost something. The man is mad with the loss of this thing and a kind neighbour—who secretly wishes to see the world through the eyes of the madman,

wherein everything is novel—creates a plan for the man to go out and look for this thing that is making him mad. Other neighbours begin to guess as to the nature of the thing, and soon many are involved in the search. The search for the thing becomes the thing itself, giving meaning, purpose and hope to the islanders; what could it be whose loss causes this much distress. The thing remains elusive and undefined, its image a metaphor (that of a kite). The clues are in the title of the novel—a madman, a kite, an island. The lack of definition or full understanding of the thing does not lessen its effect on the villagers. The thing is what it is to each person, as it has affected them personally. This seems to be as it is with mental illness and madness, something whose elusive and invisible qualities are hard to define and impossible to see. The way madness is seen, as indicated by many of the interview participants, is in part related to the context.

Those who access mental health services in Northern Ontario represent a new type of consumer in an increasingly profit driven mental health industry. Sent out or set free from the hospitals consumers and survivors of psychiatric services are wedged into an identity that promotes autonomy but in reality leads back to individualization; the problem is in the chair, so to speak. So it may be that you or I find ourselves sitting in a psychiatrist's office bartering for some sort of assistance. We have found ourselves here through a belief that this is where help will be found at last. Perhaps we have made individual choices which have led us here, but now that we are here we are held accountable to ourselves through the treatment protocol. In the present context of what Kenneth J. Gergen describes in *The Saturated Self as* "social saturation" it is difficult to unplug from the constant offerings of ways of being (Gergen 48). Gergen argues that social reality today is comprised of "manifestations of a profound pattern of social change" one that "immerses us ever more deeply in the social world, and exposes us more and more to the opinions, values, and lifestyles of others" (Gergen 49).

The omnipresent Bell Canada *Let's Talk* campaign is a recent example; in more subtle ways, through advertising, public service announcements, the urge toward self-surveillance is ever- present. For people living with diagnoses of mental illness, self-surveillance culminates in living carefully. One of the interview participants, Brent lamented that he avoids the seductive call of the heights to which his moods used to take him—it's just too risky. Cassie pulled out a pair of boots that signified for her a time when she lived in a faraway place in time and space—she misses that girl and she thinks maybe her family misses that girl too, but, too risky. Now, making her bed and getting on are the hallmarks of good living and the precarious autonomy she earns with good behaviour.

Further reflection on the state or phenomenon of mental illness in the current Canadian climate focuses on highly competitive and precarious arenas of advanced capitalism. Precarious employment brings with it a sense of insecurity and a spirit of competition that is only exacerbated by increased methods of governance. The destabilizing effects of precocity bleed into the institutions that policy makers and academics could once find solace within. That these are the institutions that make decisions about mental health, mental wellness and mental health literacy is all the more alarming. Far from a monolith that cannot be challenged, the mental health system should be under watch as its particularly fluid and dynamic forms of power flow from the bottom to the top of Canadian institutions, corporations and non-governmental and not-for-profit agencies. The challenge has already come from activist writers such as INCITE! WOMEN OF COLOUR AGAINST VIOLENCE who in 2002 "took a stand against state funding since [we] perceived that antiviolence organizations who had state funding had been co-opted" (INCITE!).

In “Security, Territory, Population” a series of lectures at the College de France, Foucault discusses governmentality and governmentalization and his process of coming to certain problems for analysis. He begins to place the question of “how to govern oneself, how to be governed, by whom should we accept to be governed, how to be the best possible governor” in the context of the history of sovereign rule (Foucault 128). He says he was led to the analysis of “some mechanisms of security” through which he had tried to “see how the specific problems of population emerged, and last week, looking more closely at these problems we were quickly led to the problem of government” (Foucault, 126). Foucault understands governmentality as “the ensemble formed by institutions, procedures, analyses and reflections, calculations, and tactics that allow the exercise of this very specific, albeit very complex, power that has the population as its target, political economy as its major form of knowledge, and apparatuses of security as its essential technical instrument” (Foucault *Technologies* 107). What follows from such a concept is that of governmentalization and an “overvaluing” of the state and all its powers, one which reduces it to “a number of functions like productive forces and the reproduction of the relations of production” (Foucault *Technologies* 107). This, he says, is a “mythica1ized abstraction” (Foucault *Technologies* 107). Foucault, after all, hints at the possibility of other ways of understanding and thus changing what were thought to be impenetrable and immutable entities.

This thesis brings into focus contemporary experiences from within the present mental health system, a system attached to an industry with an historical trajectory of medicalization, institution-building, deinstitutionalization and reformation. Through the lens of those working and managing madness within the current mental health system, individual decisions and personal technologies of management and self-management are made significant. Awareness of

the medical gaze impacts more and more Canadians each year through social media and public service announcements and products of the industry including pharmaceutical drugs and funded research which supports their claims. As people enter the system they do so in this context. The terms consumer, survivor, caregiver and stakeholder were used to indicate relationships between the interview participants and the mental health system. These terms and their concepts remain problematic in many senses and therefore open to further interrogation through the voices of the participants as well as through analyses of consumption and production such as those of Miller and Rose who write:

> We abstain from a mode of analysis which links the unholy alliance of psychology, advertising and capitalism with a manipulation of desires in the name of private profit, social anaesthesia and commodity fetishism. We are concerned with what one might term the 'productive' features of these new techniques, the ways in which psychological knowledges have connected themselves up in complex ways with the technologies of advertising and marketing to make possible new kinds of relations that human beings can have with themselves and others through the medium of goods (*Governing the Present* 116).

The interviews suggest for further exploration a type of bargaining and exchange within relationships as well as intra-relationally, with ideas of oneself that one comes through the diagnostic process. I make a distinction also between the mental health system and the mental health industry. In this concluding section I will discuss the relevance and friction of these terms as they appeared in the thesis. I used the term "consumer" because it is the term used primarily by researchers to signify, I think quite inaccurately, an increased autonomy within an over-arching system. "Stakeholder" is an equally inchoate signifier, but along with other terms is used

as a bookmark within the system; these terms are generally understood to indicate what was once understood as "the mad" and the "not mad." The mental health system refers in my work to the delivery system, its ideologies and practices as it has structured itself around the concept of a consumer. The interview participants have pointed toward what questions need to be asked next in the context of what these particular people have made visible about their experiences as survivors, consumers, caregivers and stakeholders, terms which, it is clear are markers with much limited significance to those signified. Contemporary theorizing of power, subjectivities and governmentalities as they related to madness and mental illness can only be aided in reconceptualization's of the subjects and objects of psychology, social work and, increasingly human resource management, by the words and ideas of those who have entered and exited these domains. Theories such as those of Miller and Rose in their analysis of the mobilization of the psychiatric consumer and Derek Hook in *Foucault, Psychology and the Analytics of Power* suggest also that "buried historical contents and subjugated knowledge are such vital resources for genealogical work precisely because of their potential to disrupt the dynamic between power and knowledge" (140).

The rich data and themes that continue to emerge through ongoing analysis of what people in a northern Ontario community have said about their experiences will continue to inform and synthesize the relevance of these and other theoretical assumptions about what it is to be mad in contemporary Canada, what has been lost in translation perhaps, and in what ways the mad subject will be inserted into new forms of mental health management.

Here is another image that came up again and again as I was reading very old books about very old places. When I was about six years old, my Dad told me a story when we were still living in Glasgow and it was easy for me to conjure up the required imagery. The history of

the place was everywhere there, in the centuries old churches and in the working class citizens. My Dad's story was about a tramp. The tramp had been in the habit of allowing himself to be corralled every winter into the city jail, where three meals and a cot would be provided free of charge. It would not take much of a transgression to earn this small comfort. The tramp stood outside one of the old churches in Glasgow (maybe Saint Mungo's, my mind told me), and he picked up a stone with the intention of securing his lodgings for the winter by throwing the stone at the stained glass windows.

As he stood outside the church, he heard a choir singing within and he was enchanted by the sounds, by the coloured glass windows and by the whole beautiful specter of the thing he had been about to abuse. He was overcome with an unfamiliar feeling of hope and belonging and he let the stone drop from his hand. He stood a while longer and decided he would not spend this winter locked up. He would make a clean start and get on with his new life. As he was contemplating this new horizon, a police officer came by and charged him with vagrancy. I didn't ask my Dad if there was a meaning to the story. The story was about hope and fear and the careful regulation of each. It was about a hopeful, romantic man who had no place to live.

The story, and the power of bricks and mortar to both conceal and protect, often comes back to me as I now understand the historical contexts in which both the Glasgow story and this thesis came to life. Not much later, after a schoolyard accident caused a broken leg, I was hospitalized in the same city for several weeks. The stories I had been told (O'Henry and Brer Rabbit tales) combined with this long stay in one of Glasgow's largest hospitals produced a lifelong curiosity about all institutions and the people who populated them. My curiosity is apparently widely shared as a quick search through internet blogs yields an interest in visiting abandoned hospitals, asylums, and prisons as well as many anecdotes and memories of growing

up around such institutions. As one of many cities renowned for its historical architecture it is a place also of institutional memory. Around the world, the technological landscape carries local and immediate stories and memories. Remembering the asylum in her backyard, Scara, writes:

> Gartloch was the place where the "maddies" went, even if that wis yer maw stretched oot oan a social prescription of chlorpromazine and diazepam tae stope her thinkin aboot why she just looked oot the windae at the sun goin oot…the wee red room oan the tope of the tower wus were the really mad bastards went. Ye could walk yer dug lookin fur frog spawn or something else like that and hear the alarms goin aff and then see the very expertualised nurses chasing a wanna be freedom seeker across the fields. As humans under the age of twelve, we used tae set aff the fire alarms and watch the engines screaming alang gartloch road "bloody murder" until wi gote caught and battered. Once we crawled underneath the corridors, opened a hatch and surfaced mid corridor amidst the expert's madness. They chased us tae the gates before we started peltin them wi rocks. They couldnae come oot across the gates cos they wid lose aw their powers. In winter the loch might turn tae ice but ye heard so many horror stories that ye never went far frae the edge. (Scara)

When one enters the mental health system, one becomes part of a system that thrives on maintenance rather than cure. At the top of this hierarchical system, at least if understood in terms of power, money and access to knowledge are psychiatrists, administrators, social scientists, policy makers, pharmacists and funding bodies. Somewhere in the middle layers are social workers, counsellors, occupational therapists, rehabilitation specialists, and, most recently, methadone counsellors or addiction specialists. Working and living as part of the system, are people who sometimes identify as consumers, survivors, caregivers and service providers; these

are people who are neither wholly complicit nor wholly powerless—they have resisted and adapted according to their needs.

The madness myth makes its way to people through television, literature, and the internet and has become as globalized as any other social phenomenon. Indeed, when a horrific crime is committed by someone with a mental illness diagnosis, we hear about it instantaneously and repeatedly, adding to the madman or mad woman mythology. The internet, as a social force influencing meaning making, is one of many technologies that has had an impact on the experience of mental illness. Yahoo provides a vehicle for online discussions and mad blogs. Symptoms can be checked and diagnosed online and the effects of various drugs can be discussed among the people who take them. This opens up new avenues for mad talk.

Adding to the critical ethnographic approach are reflections on a short contract I took on during the writing of the thesis. I worked for a few months at a consumer survivor initiative. In order to work at this initiative, one had to have lived experience of mental illness. I was not expected to be precise about this experience and my interpretation of what constitutes lived experience was respected. In the first week, as it happened, the agency hosted an international workshop for peer support workers. I was expected to attend the workshop and to participate. I had a great deal of trouble accepting the terms used. I had been interested in the agency and how it functioned for some time and I wanted to be honest about my position. I also knew it would be a valuable experience and I missed frontline work. The person who hired me respected my honesty. I did not claim to stand outside of the experience of madness, I don't know how anyone can, but I claimed my right to identify on my own terms. At the workshop, I found myself in one of two sharing circles in which we were expected to tell our story.

We were instructed beforehand about the value of therapeutic sharing, that our story

should be told in such a way as to be helpful to others in the circle. I was about halfway around the circle in terms of turn. I knew many of the people in the circle; they had shared their stories with me in a variety of contexts, from counselling to less formal interactions. I had carried some of these, in the tradition taught to me by First Nations elders, for many years. When it was my turn, I told my story. I was honest. I cried. It had been a long time since I had felt so naked; who has time for such indulgences?

Our stories were, for the most part, not stories of being "peers" in the mental health system, but about old wounds, deep regrets, the loss of and finding of meaning and purpose, the remapping of no longer useful roads. This palpable strength stood above and outside of any clinically ascribed and fundable definition of "peer" or "survivor." We had been through something similar, something that only those of us who have had those particular experiences could know because it was beyond words. There were no patronizing nods of the head or prescribed questions; there was eye contact and shared tears. We would easily be diagnosed as depressed for our seeming lack of control, but we could also laugh at this misdiagnosis, this stolen human expression. I could see why the term "survivor" fit so well for some people, although I contend that it is too closely linked to the consumer and the medical model. I don't deny that it has significance and resonance beyond this. We had survived. These were our own individual stories, which we had protected and honored and we had brought them out on this day to share with others. I began to see that in living rooms and coffee shops during the time it took me to complete my ethnographic research, the people I had interviewed had done the same.

At about the same time that self-described ex-psychiatric patients began to form groups and to write about their experiences in the psychiatric system, there was a backlash in the media and a return to the practice of vilifying those involved in crimes whenever it was known that they

had a history of using the services of the psychiatric system. The psychiatric patient is often depicted in the media as frightening and unreasonable and sometimes as someone who should not be legally allowed to make decisions concerning his or her treatment. The user of mental health services, while not quite conjuring up images of a mad man frothing at the mouth, shot gun in hand, should, it is subtly suggested in 1980s' news stories, be treated with caution and should certainly not be given any position of authority or leadership.

Presently, more and more of us are living carefully under the medical gaze. But, before being entirely swept up in a mediated play of the tensions and interstices of the mental illness/ mental health paradigm, one that is ever more socially inclusive as it becomes an ever more profitable industry, it is worth looking at the process of aestheticization of what is called mental illness. Where is this land of inclusion for the "one in five" of us who will "experience a form of mental illness in their lifetime"? Who are the representatives of mental illness in Canada? In a recent 62 million dollar campaign called *Let's Talk*, Bell Canada aims to "end the stigma" attached to mental illness, but could such a media and research blitz perhaps contribute to stigma? In much the same way that resiliency is sometimes analyzed as a hallmark of strength and triumph over adversity, particularly for children deemed as at risk, being identified as not being mentally healthy enough to meet the grade leaves a kind of open-ended diagnosis, one in which the viewer/reader is left to participate in a silent self-surveillance. The problem, as Bell Canada's research team sees it, is access and attention. It is not that there is a shortage of mental illness. What does it mean, and what it is like to be mad, crazy and/or mentally ill from the perspectives of people living with diagnoses of mental illness in a newly emerging social and political context?

Bell Canada's latest *Let's Talk* campaign claims Bell is trying to shed light, reduce stigma, end the silence of mental illness, but the campaign does not allow for, and in fact interrupts, an interrogation of what it is we are talking about when we stop talking about mental illness and madness in public spaces and start talking about mental health. To understand that what is called mental illness, and often self-described as madness, is at times a liminal experience, an out on a limb experience from which some people recover and repeat throughout a lifetime is to return madness to its place as another, more than ordinary experience of the senses. This is not to romanticize the other side of madness, but to get out from under the madness/reason debate which, outside of philosophy, most disciplines have been unwilling to do.

Under the medical gaze, in Foucault's sense of the term, the doctor has the authority to determine these limits. We might argue that today's mental health consumer is more informed and that he or she participates with full autonomy in the management and diagnostic process. In the present era of saturation, of the marketing of mental illness and its cure, it is hard to avoid the messages that something might be seriously wrong. It is easy to buy into the medical model and one that tends to edge out all but the most mundane as slightly, moderately or seriously pathological.

To rethink madness, to reclaim despair, fear and ecstasy which exist at the limits of human experience is a frightening prospect for most; what if we lose our minds? Interdisciplinary perspectives, such as the one offered here, make room, finally for mad voices alongside mad knowledge and mad history. These voices, including those of the interview participants in this thesis have unique knowledges about themselves, their minds, and their interactions with others. They are aware of how the system works. They tell us how the system works, what does and what doesn't help.

The participants have described their own experiences with mental illness or madness. For some, this has been primarily in relation to the hospital system, for others, in relation to other significant aspects of their lives. Consider the DSM-V, which has increasingly come under fire for trying to increase the landscape of medicine by categorizing increasing human behaviours into a pathologized version of human experience. Consider also the most recent campaigns to sweep more and more of us into this landscape.

Some people in this thesis have been asked to come forward as subjects of the psychiatric system. This is not their only subjectivity but it is this subjectivity that has been explored toward the dual aims of tracing the mad subject and adding other voices—some of them claimed as mad and all of them made to work as critical voices—to the discourses of psychiatry and mental health. In their earliest history, the insane or mad have been spoken about as public problems. In the latter part of the nineteenth century, with the rise of eugenics, they came to be regarded as a special risk For a large part of the twentieth Century they were spoken about, as research subjects, necessarily identified bodies aligned with emancipatory politics as public problems, economic burdens as well as the economic lubricant of vast systems of health care delivery and research. In the present, more mad speak from various locations within and outside of the psychiatric and mental health industry. They and we speak collectively, academically, radically and individually.

It takes a strenuous mental effort to pull the mad subject from the psychiatric system—it is a shocking thing to consider, naked-emperor like in its revelation that without the illusion of insanity, lunacy and the most frightening of all, serious mental illness, the system would cease to exist. Without the separation of groups of immigrants who pose threats to hygiene, and the ever-changing statistical threat of the number of us at risk of future experiences of unbearable despair,

all such people would remain among us in the larger numbers. This is precisely what we are witnessing in the present. Inverting the ratio and increasing the risk discourse such that many more people actually see madness or mental illness in themselves or others semantically extends to the conclusion that more and more of us should be, if not locked up, at least talking to someone. Rather than emancipating mad people, this corrals more of us into a subtle pattern of mental surveillance.

This thesis has presented a unique contribution to psychiatric, mental health and mad literature because it has worked to provide a critical analysis of psychiatric history in Ontario, has invoked experientially founded critical analysis of the historical and contemporary psychiatric and mental health systems. This bodes well for future analysis of what such emancipation might look like, not just for mad and mentally ill people but for those who do not identify as such. This invites a fuller condition of possibility of being human, with all the despair and angst that this often entails.

The last word should go to a friend of mine—a mad man really. We meet for breakfast at Frank's, which sadly has closed. We go through the riddle he gave me years ago. "Do you believe people can change?" I ask, "No" he says, "but I've seen it happen".

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Appendix 1: Questions for service providers/stakeholders:

1. What was the period of time that you were working as a service provider?
2. What was your role? (Did this change over time)
3. What were some of the governing factors in your work? (Policies, etc.)
4. Would you talk about some of the problems experienced in your work?
5. What were some of the successes?
6. What were some of the reactions to your work? When you told people what kind of work you did?
7. Where do you think these reactions or attitudes came from?
8. What theories contributed to attitudes about mental illness?
9. Were there differences in the way that people with physical illness and people with mental illness were care for or treated?

Appendix 2: Questions for mental health consumers/survivors:

1. What was the period of time that you were receiving services?
2. What was your diagnosis? (Did this change over time)
3. Could you talk about what that word meant to you?
4. Do you have any ideas about what that meant to other people? (Family, friends)
5. What were some of the successes that you have experience to do with having been diagnosed with a mental illness?
6. What were some of the problems you experienced?
7. Where were some of the general attitudes toward mental illness?
8. Where do you think these ideas came from? What theories contributed to these ideas?
9. Were there differences in the way that people treated you? Did your roles change?

Appendix 3: Ethics Review